Evaluation of the Impact of Making HIV a Reportable Infection in British Columbia

October 2006

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MBBS, MSc, FRCPC, OBC
Provincial Health Officer

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Evaluation of the Impact of Making HIV a Reportable Infection in British Columbia

October 2006

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MBBS, MSc, FRCPC, OBC
Provincial Health Officer

2007-01344/

October 13, 2006

Honourable George Abbott
Minister of Health
Room 337
Parliament Buildings
Victoria BC V8V 1X4

Dear Minister Abbott:

Re: Provincial Health Officer's report on HIV Reportability

In February of 2002 I released a report studying the proposal to add HIV to the list of reportable diseases in British Columbia. The report's findings, following a targeted consultation with stakeholders and an extensive literature review, may be summarized:

"The published literature on the impact of reportability suggests that the main benefits accrue in the areas of enhanced epidemiological surveillance and partner notification. It is clear that improved partner notification substantially shortens the time from infection to diagnosis, and is generally appreciated by those identified and counselled. However, beneficial impacts on HIV epidemics, i.e., diminished spread of the disease, are not established.

The potential adverse effects or making HIV reportable, that were raised during consultation include: that reportability is accompanied by breaches of confidentiality, induces a reluctance to come forward for testing, promotes avoidance of testing, and results in increases in repressive measures against HIV infected persons. These adverse effects are NOT borne out in the literature reviewed. Nonetheless, they remain valid concerns and I recommended that should be addressed in any public health schema for HIV disease prevention and control.

A review of the then-current reporting system in BC suggested that the main benefits of reportability of HIV in this province would be in the area of partner notification, with a potential shortening of the time from infection to diagnosis and treatment/counselling. This would, however, be contingent upon a reallocation of resources to index case interviews and subsequent partner notification. The consultation raised several issues of concern around the present system of HIV diagnosis and follow up, and these were also addressed in the report.

The report-"Provincial Health Officer's report on HIV Reportability" made the following seven recommendations:

1. HIV should be added to the list of reportable conditions in Schedule A of the Health Act Communicable Disease Regulation.

2. A non-nominal option should be available for persons being voluntarily tested who do not wish their names to be reported to the public health authority.

3. Physicians, other health professionals, and all persons likely to view HIV test results should be informed of their duty under the *Health Act* to maintain confidentiality around the information contained in such reports.

4. Physicians and other persons offering HIV testing should be aware of the requirements for informed consent and the necessity of adequate pre-test counselling.

5. Adequate resources must be available for patient counselling and partner notification, counselling, and follow up.

6. Best practices protocols for enhanced partner notification should be developed and disseminated, and the process of public health partner notification should be subjected to continuous quality control.

7. The impacts of making HIV reportable should be the subject of an evaluation. If the net impact is determined to be a negative one (as measured against preset criteria), steps should be taken to remedy specific problems, or HIV should be taken off the list of reportable conditions.

In May of 2003 HIV was, through an Order in Council, added to the list of reportable diseases, schedules A and B of the communicable disease regulation was amended to allow for a non-nominal option to be presented to patients, and letters were sent to all physicians in the province alerting them to the change. Subsequent letters were sent to physicians and laboratories, reminding them of the requirements and clarifying the processes for non-nominal reporting.

In addition, the Division of STI/HIV Prevention and Control at the BC Centre for Disease Control was asked to conduct an independent third party evaluation of the impacts of the changes to the communicable disease regulation.

This evaluation was funded by the Vancouver Foundation and commenced on September 1, 2003.

I am pleased to issue the results of this evaluation as a PHO Special Report with limited distribution.

The study's key findings and recommendations are:

Key Findings:

No significant differences in the trends of HIV testing, nor rates of HIV positive cases per 100,000 population, overall or by gender were observed comparing the periods before and after the introduction of HIV Reporting and follow-up. A very positive impact has been the involvement of Public Health in partner elicitation for approximately half of the newly positive cases providing a consistent approach to case management.

Overall, public health involvement in case management has been well received by Index Cases, Contacts and Physicians. Of concern is that 25 – 30 per cent of Physicians report not informing their patients about critical issues pertaining to HIV Reporting during pre-test counselling. Four official Critical Incident Reports were received related to breach of confidentiality and threats of harm subsequent to HIV Reporting. One of these involved fear of being harmed rather than the occurrence of actual harm.

Key Recommendations:

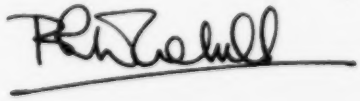
1. Since the process of making HIV a reportable infection in BC was a consultative one, appropriate feedback of the findings of this evaluation to stakeholders must follow.
2. This evaluation has underscored on-going problems with the implementation of the non-nominal testing and reporting option. These concerns must be addressed.
3. Individuals considering and being referred for HIV testing should understand that they have the option of nominal or non-nominal testing and reporting. Communications to profile and support HIV testing should be reviewed and appropriate information concerning these choices should be emphasized.
4. Ongoing education of all stakeholders is required to maintain confidentiality and to improve the quality of patient counselling, referral, testing and HIV Reporting activities.
5. A domestic violence strategy needs to be developed for persons who have experienced or are vulnerable to violence because of disclosure of HIV positivity.
6. On-going monitoring, evaluation and research should focus on the following:
    a. Qualitative indicators to explore concerns from Index Cases and Contacts;
    b. monitoring HIV testing volume and HIV positive rates;
    c. Medium and longer term impacts of mandatory HIV Reporting on service provision.

As Provincial Health Officer, I wish to acknowledge and thank the many people who have contributed to this report including the organizations listed in Appendix 9, as well as all individuals surveyed. Special thanks to Darlene Taylor, Dr. Malcolm Steinberg, Elsie Wong, Linda Knowles, Daphne Spencer, Dr. Timothy Christie, Dr. Gina Ogilvie, and Dr. Michael Rekart who assisted in the report's preparation.

This evaluation was made possible through the financial assistance of the Vancouver Foundation.

I support the recommendations made by the evaluation team and commit to working to address them.

Sincerely,



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Evaluation of the Impact of Making HIV a Reportable Infection in British Columbia

October 2006

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Submitted to: The Vancouver Foundation
Submitted by: Division of STI / HIV Prevention and Control, BCCDC

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ACRONYMS

ASO	AIDS Service Organization
BCCDC	British Columbia Centre for Disease Control
CIF	Critical Incident Form
CRF	Case Report Forms
FTE	Full Time Equivalent
HA	Health Authority
HSDA	Health Service Delivery Area
IDU	Intravenous Drug User
MHO	Medical Health Officers
MSM	Men who have Sex with Men
PCRS	Partner Counseling Referral Service
PHO	Provincial Health Officer

EXECUTIVE SUMMARY

Background: Surveillance of HIV infections has been shown to enhance the prevention and control of HIV/AIDS. Prior to making HIV a reportable infection in BC, the Provincial Health Officer (PHO) undertook community consultations in BC to inform this decision. These yielded concerns that HIV Reporting would result in breaches of confidentiality, reluctance to come forward for testing, and increases in repressive measures against HIV infected persons. As a result, the PHO recommended that an evaluation be conducted of this newly mandated surveillance and follow-up activity.

Objectives: To determine the impact of making HIV infection reportable in British Columbia during the first two years of reporting beginning 1 May, 2003.

Methods: HIV testing and HIV infection data were collected from the HIV surveillance and the Provincial Laboratory databases and analyzed for trends. Index Cases, Contacts, Public Health Nurses, Physicians, and HIV/AIDS Community Service Organizations were surveyed using self-administered questionnaires. In preparation for the evaluation, community members and particularly Aboriginal groups were consulted in the planning stages to identify and resolve potential barriers for the study.

Results: No significant differences in the trends of HIV testing, nor rates of HIV positive cases per 100,000 population, overall or by gender were observed comparing the periods before and after the introduction of HIV Reporting and follow-up. A very positive impact has been the involvement of Public Health in partner elicitation for approximately half of the newly positive cases providing a consistent approach to case management. Overall, public health involvement in case management has been well received by Index Cases, Contacts and Physicians. Of concern is that 25% to 30% of Physicians report not informing their patients about critical issues pertaining to HIV Reporting during pre-test counseling. Four official Critical Incident Reports were received related to breach of confidentiality and threats of harm subsequent to HIV Reporting. One of these involved fear of being harmed rather than the occurrence of actual harm.

Key Recommendations:

1. Since the process of making HIV a reportable infection in BC was a consultative one, appropriate feedback of the findings of this evaluation to stakeholders must follow.
2. This evaluation has underscored ongoing problems with the implementation of the non-nominal testing and reporting option. These concerns must be addressed.
3. Individuals considering and being referred for HIV testing should understand that they have the option of nominal or non-nominal testing and reporting. Communications to profile and support HIV testing should be reviewed and appropriate information concerning these choices should be emphasized.
4. Ongoing education of all stakeholders is required to maintain confidentiality and to improve the quality of patient counseling, referral, testing and HIV Reporting activities.
5. A domestic violence strategy needs to be developed for persons who have experienced or are vulnerable to violence because of disclosure of HIV positivity

6. Ongoing monitoring, evaluation and research should focus on the following:
   a. Qualitative indicators to explore concerns from Index Cases and Contacts
   b. Monitoring HIV testing volume and HIV positive rates
   c. Medium and longer term impacts of mandatory HIV Reporting on service provision.

INTRODUCTION

On 1 May 2003, the British Columbia *Health Act* Communicable Disease Regulation, BC Reg. 4/83, was amended to add HIV to the list of reportable infections[1] bringing BC in line with all other provinces and territories in Canada.[2] This legislative change requires that positive HIV test results be reported to regional Medical Health Officers (MHOs) in either a nominal/name-based or non-nominal/non-identifying format, depending on the testing option under which consent for testing was obtained.[3] The non-nominal provision is to ensure that people at risk are not deterred from testing by concerns over privacy.

The rationale for HIV Reporting is to allow better management of HIV positive patients, more complete and prompt notification of Contacts, and a more precise picture of local HIV epidemiology. However, achieving these objectives, which would improve HIV/AIDS control through enhanced, care, support and prevention, requires a primary care partnership involving the patient, the provider, and public health.[4]

The need for this partnership and the failure of the B.C. Communicable Disease Policy Advisory Committee to reach a consensus about HIV Reporting following the recommendation of the Health Officer's Council to make HIV a reportable condition prompted an extensive iterative community consultation. Conducted between 2000 and 2002 by the BC Provincial Health Officer (PHO), this consultation sought to appreciate community issues regarding adding HIV to the list of reportable infections in BC. Community stakeholders were almost unanimous in opposing reporting. Concerns expressed included fears that making HIV a reportable condition would result in breaches of confidentiality, reluctance to come forward for testing and/or delays in testing, increases in discrimination against HIV infected persons and coercive measures to change behaviours and name partners by the public health system or other organs of government. More specifically, fears were expressed that reporting requirements would have particular negative impact on Aboriginal people, women (or men) in abusive relationships, on street oriented youth, and on persons living in smaller communities.[5]

In response to these concerns, the PHO recommended that "the impacts of making HIV reportable should be the subject of an evaluation". The PHO added that "if the net impact is determined to be a negative one (as measured against preset criteria), steps should be taken to remedy specific problems, or HIV should be taken off the list of reportable conditions".[6] The Division of STD/AIDS Control at the BC Centre for Disease Control (BCCDC) was asked to conduct this evaluation and succeeded in obtaining funding from the Vancouver Foundation (Grant: BCM03-0096) for this. In addition, the PHO compiled and disseminated best practices for seeking informed consent, maintaining confidentiality, and partner notification[i] activities[7,8] This was complimented by a description of the impact of HIV Reporting on HIV pretest counseling[9] and guidelines for Public Health Nurses for follow-up of newly identified HIV cases in BC.[10]

EXPERIENCES OF HIV REPORTING OUTSIDE BC

The expansion of national surveillance to include both AIDS cases and HIV infection has occurred worldwide in response to the impact of advances in antiretroviral therapy, the implementation of new HIV treatment guidelines, and the increased need for epidemiologic data regarding persons at all stages of HIV disease. This has provided some scope to assess the impacts of this additional surveillance initiative outside the province of BC[11,12]

IMPACT ON SURVEILLANCE

Advances in antiretroviral treatment and its impact on lengthening the period between HIV infection and AIDS (AIDS incubation time or 'time to AIDS')[13] have led to a decline in AIDS incidence and have diminished the ability of AIDS surveillance data to represent trends in the incidence of HIV infection or the impact of the epidemic on the health-care system.[14] This has also been evident in BC where there was a decline in AIDS case reports from 358 in 1993 (10.0 per 100,000) to 99 in 2004 (2.4 per 100,000).[15]

HIV case surveillance provides better data to characterize populations in which HIV infection has been newly diagnosed, including persons with evidence of recent HIV infection such as adolescents and young adults. This is demonstrated by a review of reported HIV infections and AIDS cases from January 1994 to June 1997 from 25 states in the USA, which showed that 14% of all reported HIV cases occurred in persons aged 13-24 years but only 3% of reported AIDS cases occurred in this age range. Compared with persons reported with AIDS, those reported with HIV infection in these 25 states were more likely to be women and from racial/ethnic minorities. In addition, in these 25 states, the total number of persons who were reported as living with either a diagnosis of HIV infection or AIDS was 133% greater than that

[i] The term 'partner notification' evolved in the 1980s from an expansion of 'contact tracing', first coined in the 1930's by U.S. Surgeon General Thomas Parran. However, given the stigma and potential discrimination towards those infected and affected by HIV a greater sensitivity towards this public health activity resulted, in the late 90s, in a more enabling term - HIV Partner Counseling and Referral Services (PCRS). This is felt to be a more accurate reflection of the range of services available to HIV-infected persons, their partners, and affected communities. This use of this term is being encouraged in BC.

represented by the number living with AIDS alone. [16] This indicates that the combined prevalence of those living with a diagnosis of HIV infection and those living with AIDS provides a more realistic and useful estimate of the resources needed for patient care and services than does AIDS prevalence alone.

Impact on HIV Testing Behaviour

Wherever HIV Reporting has been added to surveillance activities, concerns have been expressed about potential impacts on testing practices or behaviour. However, this is not supported by findings in the literature. Other Canadian provinces, in which HIV Reporting is well established, have not appeared to have experienced adverse effects of reporting on HIV testing overall or in any sub-population, although data is sparse.[17] More scientific evaluations of this potential impact have confirmed the lack of adverse effects. As pointed out by the PHO in his report following his community consultations, a comprehensive review of the impact of nominal reporting in the USA found no consistent adverse impact, either overall or in any specific sub-population when post-reporting testing requisition numbers are compared with pre-reporting testing data.

As the PHO emphasized, the literature suggests that delays in testing are more likely due to apprehension about subsequent test results than concerns over public health involvement.[18,19,20,21]

However, reported studies that have analyzed determinants of test-seeking or test-avoidance in relation to policies and practices on HIV testing and reporting suggest that while reporting has had little impact on testing behaviour overall it may have had a marginal impact on vulnerable populations with a decrease in this impact over time. As early as 1988, a general population study of previous or planned use of HIV testing services did not identify an association of reporting policy with testing behavior.[22] This is balanced by findings from interviews of persons seeking anonymous testing[ii] in 1989, which documented that many would avoid testing if a positive test resulted in name reporting or partner notification. [23] It has since been accepted that those at high risk of HIV infection or those who would not volunteer for testing under nominal or non-nominal circumstances are more likely to seek this testing option.[24,25,26]

A CDC study conducted a decade later, in collaboration with six state health departments in the US, reviewed data routinely collected from these sites to compare HIV testing patterns during the 12 months before and the 12 months after implementation of HIV case surveillance. The data did not suggest that, in these states, the policy of implementing HIV case reporting adversely affected test-seeking behaviors overall. The most commonly reported factors (by nearly half of respondents) that might have contributed to delays in seeking testing or not getting tested were fear of having HIV infection diagnosed or belief that they were not likely to be HIV infected. However, when these data were examined by risk group, "reporting to the government" was a concern that might have contributed to a delay in seeking HIV testing for 11% of heterosexuals, 18% of injecting-drug users, and 22% of men who have sex with men. While less than 1%, 3%, and 2% of respondents in these risk groups, respectively, indicated that this was their main concern and was only slightly increased if this reporting was nominal, this did increase to 28% for MSMs and was the main factor for not testing for HIV for 4% of this risk group. The survey also documented that the availability of an anonymous testing option was consistently associated with higher rates of intention to test in the future. [27,28]

[ii] ***Anonymous testing*** is testing in which the results can be linked to the person being tested by a code known only to the patient/client. Thus, while the care giver who ordered the test and/or provided pre-test counseling can visually identify the person who was tested he/she is not able to link any result with that person. The person being tested is able to access their result by, for example, confidentially entering their code into a computer data base to retrieve their result. This is not available in BC. However, individuals are able to obtain a ***flexible non-nominal testing*** option where testing is conducted without having to disclose one's true name. In this instance any care giver who is involved with discussing the result of the test with the person who had the test is not aware of the true identity of their client/patient. However, this option may involve collection of patient information (such as age, gender, city of residence, name of diagnosing health care provider, country of birth), information detailing the HIV-related risk factors of the person being tested, and laboratory data. This option is only offered by some specialized primary care sites but is not available in a physician's office. With ***non-nominal testing*** the HIV test is ordered using a code or the initials of the person being tested (not the full or partial name) but the person ordering the test knows the identity of the person being tested for HIV and the result of the test is entered into the confidential patient/client health care record. In BC, these latter two options are both referred to as non-nominal testing options.

More recent studies from the US seem to indicate that concerns about HIV Reporting are dissipating further and that fear of disclosure (to government, insurance agency/employer or "someone" else) is an infrequently cited reason and least likely reason for deferring or delaying testing.[29] In addition to confirming this, a further study has demonstrated increasing awareness of HIV Reporting and PCRS services with higher awareness among MSMs (61%) and lowest among heterosexuals (39%). It is noteworthy that MSMs were found in this study to be the most skeptical of the program.

Impacts of Harm to Index Cases

During his community consultation, the PHO was presented with concerns of harm to infected persons living in an abusive relationship as a result of HIV Reporting and partner notification. He responded that proactive planning and sensitive intervention strategies are required in any situation where there is known infection of one partner with a communicable disease in an abusive dyad, whether or not HIV is reportable. The PHO maintained that guidelines for index case follow-up will need to include detailed protocols as well as local arrangements between public health officials and agencies providing support to abused persons.

A study reported from New York indicates the difficulty of substantiating these concerns and more specifically separating harm in abusive relationships as a result of HIV Reporting from other causative factors. Three populations at risk for HIV were sampled at three different venues in upstate New York (men who have sex with men at gay bars, injection drug users at syringe exchange programs and high-risk heterosexuals at sexually transmitted disease clinics). 335 individuals were interviewed about their knowledge of, attitudes toward and experience with the New York State HIV Reporting and Partner Notification Law; the factors that influenced their HIV testing practices; their experience with intimate partner violence and its relationship to partner notification; and their risk behavior. The survey of high-risk individuals found little evidence that New York State's HIV Reporting and partner notification law is deterring HIV testing. In fact fear of disclosure (to government, insurance agency/employer or "someone" else) was among the least likely reasons for avoidance or delay. However, the survey did uncover high rates of intimate partner violence. These were highest among high-risk heterosexuals, with 78% experiencing one or more acts of violence committed by a current or former partner. High levels were also reported among IDUs (65%) and MSMs (60%).[30]

While this survey was not able to associate these episodes of intimate partner violence with HIV Reporting it did emphasize the implications of HIV Reporting on how HIV partner notification is conducted in New York State and supports the steps taken by the PHO and others in BC to highlight best practices in PCRS as part of the HIV Reporting initiative in the province. The survey also highlights the intersection of domestic violence and HIV/AIDS and the importance of the routine incorporation of domestic violence screening into primary and preventive care.[31] Recommendations on how to approach this have been suggested by the New York State Department of Health.[32,33]

It is interesting to note that concerns expressed in the community consultation conducted by the PHO focused more on potential violence as a result of HIV Reporting and less on potential partner separation. One study that provides some encouragement that this is not a significant concern comes from an assessment of 50 individuals with HIV infection in an urban setting in Portugal. Results showed that disclosing HIV infection to main sexual partners was frequent in this sample and that despite individuals' beliefs, disclosure of HIV infection did not engage in separation processes and rupture in relationships, nor lead to disruption in relationship per se.[34] This study supports other findings of a low rate of relationship disruption after disclosure of HIV serostatus.[35,36] Two other studies identified suggest that unmarried sexual partners are the most likely to suffer a break-up in their relationships following disclosure.[37,38]

The concerns raised during the community consultation conducted by the PHO together with the experiences of HIV Reporting outside the province of BC prompted the following **objectives for the impact evaluation** covered in this report. These were:

1. To describe the impact of reporting on HIV epidemiological surveillance efforts and processes.
2. To determine whether making HIV a reportable condition resulted in a decrease in people's willingness to come forward for HIV testing.
3. To describe the impact of HIV Reporting on PCRS activities.
4. To describe the nature and incidence of harm to Index Cases, their Contacts, Public Health Nurses, primary care givers, and community agencies as a result of HIV becoming reportable.
5. To assess the adequacy of resource allocations to support HIV Reporting.
6. To assess perceptions of cases, Contacts, primary care givers and community agencies concerning the involvement of Public Health Nurses in case management.
7. To determine the impacts of mandatory reporting of HIV data on the provision of health care services to HIV positive people.

METHODS

The evaluation commenced on 1 Sept 2003 and two years of prospective HIV data were collected from Index Cases and Contacts, Public Health Nurses, Physicians, AIDS Service Organizations, and Medical Health Officers, using self-administered questionnaires. This is described in more detail below for each of these groupings.

Critical attention was paid to consulting with the Aboriginal AIDS Service Organizations to ensure full understanding of the evaluation process and to discuss any potential barriers to the implementation of the evaluation. Consultation approaches included meetings with Healing Our Spirit board members, attendance at an Aboriginal Harm Reduction Conference (It's Our Culture – Let's keep it Safe, Richmond 2003), and several planning meetings that included the Community Medicine Specialist of the Pacific Region of the First National Inuit Health Branch. Letters of support for the evaluation were also obtained from a number of Aboriginal ASOs including Red Road HIV/AIDS Network Society.

To determine the impact of HIV Reporting on HIV testing behaviour and the number of people testing newly positive for HIV per annum, the number of HIV tests and newly diagnosed HIV cases per annum after 1 May 2003[iii] was compared to the previous five years, 1 May 1998 to 30 April 2003, respectively. This information was obtained from the BC Provincial Laboratory database. HIV risk data, demographic data, and incidence of harm for all newly positive Index Cases in BC during the study period were collected from the HIV surveillance database.

For the purposes of this evaluation "harm" has been defined as any loss of or damage to a person's right, property, or physical or mental well-being[39] *as a direct result of reporting and/or any incidents of breach of confidentiality resulting from the reporting process*. Incidents of harm that occurred as a direct result of the reporting process and that were explored for in the questionnaires included:

- A breach in confidentiality such as:
    - Healthcare worker discloses name (or identifying information) of case to contact without permission.
    - Healthcare worker discloses identify of case to third party without permission.
    - Contact discloses identity of case to third party without permission.
- Harm to a case from a contact as a result of contact tracing.
- Harm to contact from a case as a result of contact tracing.
- Harm or threats to public health nurse or healthcare worker doing contact tracing from a case and / or a contact

All questionnaire data was entered into EpiData 3.0 and imported into SPSS 12.0 for analysis. Frequency analysis was conducted on all categorical data. Normally distributed continuous data was summarized using means and standard deviations, and skewed continuous data was summarized using medians and ranges. Chi square tests were performed to compare frequencies of categorical data in multiple groups. Median age of Index Cases who completed the questionnaires was compared with the median age of newly positive adults (=>18) in the province in the same time period using a Mann-Whitney U test. Open-ended questions were reviewed and concepts that occurred more than once were compiled and summarized. HIV testing data was subjected to simple linear regression analysis to assess trends before and after HIV Reporting.

[iii] The study period for the surveillance data was from 1 May 2003 – 30 April 2005. This differs to the period for the questionnaire data which was from 1 September 2003 – 31 August, 2005 due to a delay in ethics approval.

Index Cases and Contacts

Self-administered questionnaires were developed for newly diagnosed individuals (Index Cases) and persons who were named as a contact to an Index Case (Contacts). See Appendix 1 (Index Cases) and Appendix 2 (Contacts). Initially, Physicians and PHNs were asked to invite participation from Index Cases and their Contacts during their interaction with these individuals without offering an incentive. At a later stage, AIDS Service Organizations and private laboratory services in BC were requested to assist in increasing the rate of recruitment. This may have resulted in an over-representation of Aboriginal index cases and contacts surveyed for this evaluation. These respondents were offered financial incentives to participate ($10 per respondent). The AIDS Service Organizations were provided with matching funds for each participant successfully recruited. All Contacts were eligible for participation regardless of their HIV sero-status. Additional information pertaining to the Index Cases and Contacts was collected from the Case Report Forms (CRF) developed for reporting purposes. See Appendix 3. A PHN Activity Worksheet was developed to capture details such as numbers of partners identified, contacted and notified per index case. See Appendix 4. These forms were completed by Health Authority PHNs designated to HIV Reporting and contact tracing; and the forms were submitted to the evaluation team every 8 weeks. Summary information recorded from these various forms included:

1. The number of Index Cases followed up by public health versus the primary physician.
2. The opinion of Index Cases and their Contacts regarding the support that was provided by public health.
3. The number and nature of incidents of harm including physical harm, emotional harm and breaches of confidentiality.
4. The number of Index Cases that were aware, at the time of testing: a) that HIV was reportable, b) that one could test either by the nominal and non-nominal option and c) of recommendations re: contact tracing (PCRS).
5. The reasons for coming forward for HIV testing.
6. The number of Contacts elicited per case.

Initially, the questionnaires were provided to Index Cases and their Contacts directly by the health care provider (physician or public health nurse) responsible for doing HIV follow-up. They were advised to provide the questionnaires after all the required reporting documentation had been completed and at a time considered most appropriate for the clients. Clients were provided a private space to complete the questionnaire, place it in a sealed envelope, and give it back to the health care provider. The questionnaire was then forwarded to the evaluation team at the BCCDC for analysis. After one year, recruitment of Index Cases and Contacts was enhanced by asking Community Service Organizations and private laboratories to make evaluation questionnaires available to their clients.

The proportion of hard to reach individuals amongst the HIV positive cases is significantly higher in Vancouver than in other areas of British Columbia. For this reason a sub-analysis of the data from the PHN Activity Worksheet was conducted looking at Vancouver separately from the remainder of the province.

Information about incidents of harm was retrieved from Index Case questionnaires and from the Critical Incident Form submitted by health care providers. See Appendix 5. In addition, Index Cases and Contacts provided information about incidents of harm on their evaluation questionnaires. Additional information about incidents of harm was gathered from the Case Report Forms that were submitted to the HIV surveillance nurses for reporting purposes.

Public Health Nurses

A self-administered questionnaire was developed for Public Health Nurses (PHNs) designated as HIV Reporting nurses. See Appendix 6. These questionnaires were mailed out at 7 and 24 months after HIV became reportable. Details of PHN activities were also collected on the PHN Activity Worksheet. Outcomes measured included the following:

1. The number of Index Cases followed up by public health versus the physician.
2. PHNs' perception of public health involvement and its impact on case management.
3. Resources expended on HIV Reporting.
4. The number and percentage of Contacts actually reached by the PHN.

In addition to this questionnaire, PHNs were given opportunities to provide the evaluation team with information about HIV Reporting through one-to-one interviewing and group discussions although this was not originally included in the study design. The anecdotal information provided during these interactions is summarized as an Addendum to this report and serves to complement the main findings.

Physicians

A self-administered questionnaire was developed for Physicians who had at least one patient who tested newly positive for HIV after reporting came into effect. See Appendix 7. In an effort to maximize response rates, the questionnaire was limited to one page and did not include questions regarding resource utilization related to HIV Reporting activities. Questionnaires were mailed out at 7 and 24 months after HIV became reportable. Outcomes measured include the following:

1. Recommended elements of HIV Reporting that were routinely provided in pre-test counselling, e.g. the option of non-nominal reporting.
2. The Physicians' perception of public health involvement and improvement in case management.
3. Estimated number of Contacts reached by Physicians.

The number of cases followed by Physicians versus PHNs was captured on the PHN Activity Worksheet.

AIDS Service Organizations

A self-administered questionnaire was developed for Community Organizations serving HIV/AIDS clients. See Appendix 8. A list of these organizations was created using the Red Roads HIV/AIDS Network mapping and service directory[40] and other HIV directories and links found on the World Wide Web such as the Pacific AIDS Network member's directory[41]. All organizations identified were provided with a questionnaire including those organizations that attended the 'Renewing Our Response Forum' held March 17-18, 2005. See Appendix 9 for a list of the organizations included in the survey. Outcomes measured included the following:

1. The level of knowledge about HIV Reporting that is required for public education and awareness.
2. The overall perceptions (positive or negative) of regarding HIV Reporting.
3. Resource expenditure on HIV Reporting.
4. Awareness of specific harm as a result of reporting.

Medical Health Officers

All Medical Health Officers were asked to complete a self-administered questionnaire to be returned via email or Canada Post. See Appendix 10. Outcomes measured included the following:

1. The timeliness of HIV testing data received by MHO.
2. The quality and usefulness of the data to assist with the planning and implementation of programs.
3. Assessment of whether or not the MHOs are actually using this data to plan and implement services.

RESULTS

Response Rates

Table 1 shows the response rates for questionnaires sent to the various health care professionals and Community Organizations. PHNs had the highest response rate (80%) probably reflecting the encouragement given to them to participate in this evaluation and their pivotal role in the process of HIV Reporting and follow-up. There is also ongoing contact between the STD/AIDS Control Division at BCCDC which likely had an impact on this high response rate. A number of duplicate questionnaires were returned from the same Community Agency having been completed by different persons in the Agency. This indicates that respondents from these agencies may have not consulted their colleagues when completing the questionnaire which may have resulted in incomplete and/or biased information from an organizational point of view. These duplicate returns were only counted once in determining the response rate.

Table 1: Response rate to Evaluation Questionnaires

Study Group	Mailing Interval (months post Reporting)	Number of questionnaires distributed	Number of questionnaires returned	Response Rate
PHN	7	29	29	100%
PHN	24	35	22	63%
PHN Total	7-24	64	51	80%
Physician	7	189	65	34%
Physician	24	259	61	24%
Physician Total	7-24	448	126	28%
Medical Health Officer	24	22	11	50%
Community Agencies	24	51	24	47%

Demographics of Index Cases and Contacts

A total of 137 Index Cases (87 male; 50 female) agreed to complete an evaluation questionnaire. These cases comprised 15% of all new HIV positives during the study period. Thirty-four Contacts volunteered to participate which constitutes 8.6% of all Contacts approached by the PHNs during the PCRS process (n=397). Table 2 provides the demographic profile of Index Cases and Contacts who responded to the questionnaire. The gender and ethnicity breakdown among the participating Index Cases are statistically different to that of all newly positive persons in BC during the same time period ($p=0.0007$ and $p=0.001$ respectively) confirming that this small number of Index Cases is not a representative sample. This may be explained by the higher number of First Nations/Inuit/Metis AIDS Service Organizations in BC coupled with a greater interest from these organizations and the Index Cases they serve to respond to financial incentives to complete and return questionnaires. The persons served by these organizations predominantly fall into a heterosexual epidemic pattern. This could explain the greater proportion of female Index Cases returning questionnaires compared to the gender breakdown of all Index Cases in BC.

Table 2: Demographics of Index and Contact Cases who completed an evaluation questionnaire

	Contacts Surveyed n = 34	Index Cases Surveyed (A) n = 137	All Index Cases in BC during study period (B) n = 884	Comparison of A to B
Gender				
Male	21 (61.8%)	87 (63.5%)	668 (75.6%)	p = .0007 (Chi square test with Male and Female only)
Female	12 (35.3%)	50 (36.5%)	201 (22.7%)	
Transexual	1 (2.9%)	0	0	
Unknown	0	0	15 (1.7%)	
Total	**34 (100%)**	**137 (100%)**	**884 (100%)**	
Age (yrs)				
Median (range)	35 (21-51)	40 (18-71)	39 (18-82)	p = 0.65 (Mann-Whitney U 2-tailed test)
Race				
Caucasian	20 (58.8%)	95 (69.3%)	531 (60%)	
Arab.West Asia	0	1 (0.7%)	2 (0.2%)	
Asian	1 (2.9%)	4 (2.9%)	59 (6.6%)	p = <.001 (Fisher's Exact test)
Black	0	2 (1.5%)	39 (4.4%)	
First	4 (11.8%)	33 (24.1%)	122(13.8%)	
Nations/Inuit/Metis	0	1 (0.7%)	32 (3.6%)	
Hispanic	0	0	12 (1.3%)	
Other/Mixed	9 (26.5%)	2 (1.5%)	87 (9.8%)	
Unknown	**34 (100%)**	**138 (100%)**	**884 (100%)**	
Total				
Employment				
Full time	14 (41.2%)	36 (26.3%)	Not available	
Part time	3 (8.8%)	12 (8.8%)		
Disability	6 (17.6%)	28 (20.4%)		
Unemployment	3 (8.8%)	9 (6.6%)		
Social Assistant	6 (17.6%)	40 (29.2%)		
Other	2 (5.9%)	12 (8.7%)		
Total	**34 (100%)**	**137 (100%)**		
Yearly Household Income			Not available	
<$10,000	9 (26.5%)	60 (43.8%)		
$10,000-under $30,000	12 (35.3%)	34 (24.8%)		
$30,000 – under	4 (11.8%)	15 (10.9%)		
$50,000	6 (17.6%)	15 (10.9%)		
$50,000 or greater	2 (5.9%)	7 (5.1%)		
I don't know	1 (2.9%)	6 (4.4%)		
Total	**34 (100%)**	**137 (100%)**		

Epidemiological Surveillance Efforts/Processes

Changes as a result of reporting

Prior to HIV becoming reportable, public health involvement in case management was optional and limited to infrequent verbal assistance from the HIV surveillance nurses at BCCDC. At the onset of HIV Reporting, Public Health Nurses in each health service delivery area (HSDA) were informed of each new case and were given the responsibility of communicating with the primary health care provider to determine if the case was to be followed by public health or by the physician. PHN and Physicians were responsible for determining the index's cases preferences regarding PCRS.

HIV Reporting training sessions were offered to PHNs designated to HIV Reporting from each Health Authority. Initially, HIV Reporting duties were added to pre-existing PHN responsibilities for all Health Authorities with the exception of Vancouver. where 2 PHNs were assigned HIV Reporting as their sole responsibility. HIV Reporting responsibilities include case counselling, partner elicitation, and other issues related to HIV follow-up. PHNs communicated with Physicians to determine whether Reporting duties (e.g. mandatory documentation) and follow-up duties would be conducted by the PHN, the physician or both.

Reporting Duties

PHNs documented the details of who conducted case counselling, partner elicitation/notification and completion of mandatory reporting documentation on the PHN Activity Worksheet. Table 3 describes how these responsibilities were shared between PHN and Physicians. Overall, Physicians conducted 56.5% of case counselling and 52.7% of partner elicitation duties while the PHNs assumed 53%of the documentation duties. It should be noted that the experience of Vancouver is distinctly different from non-Vancouver areas where the PHNs assumed the majority of all these duties. This is likely related to the large number of new cases in Vancouver coupled with delays in hiring and assigning PHNs to HIV Reporting duties with the consequence that most case counseling and partner elicitation was done by Physicians in the early days.

Table 3: Distribution of PHN and Physicians HIV Reporting Duties

	PHN (A)	Physician (B)	Both PHN and Physician (C)	Chi Square Test of Significance between A and B (in BC)
Case Counselling (n=657)				
BC	**243(37.0%)**	**371(56.5%)**	**43 (6.5%)**	p = <.001
Vancouver only	101 (24.2%)	295 (70.3%)	23 (5.5%)	
Non-Vancouver	142 (59.4%)	76 (32.2%)	20 (8.37%)	
Partner Ellicitation (n=617)				
BC	**283 (45.9%)**	**325 (52.7%)**	**9 (1.5%)**	p = .019
Vancouver only	122 (31.8%)	260 (67.2%)	4 (1.0%)	
Non-Vancouver	161 (69.1%)	65 (28.8%)	5 (2.2%)	
HIV documentation (n=693)				
BC	**367 (53.0%)**	**243 (35.0%)**	**83 (12.0%)**	p = .001
Vancouver only	184 (42.1%)	214 (48.7%)	41 (9.2%)	
Non-Vancouver	183 (71.5%)	29 (11.7%)	42 (16.8%)	

PRE-TEST COUNSELLING

Table 4 depicts what Index Cases and Contacts recalled being told at the time of testing and also shows what Physicians reported communicating to these clients. Overall, 37% of Index Cases recalled being informed that HIV is now reportable; 39% recalled being told that there is a non-nominal option; and 51% that PCRS would be recommended if their test came back positive. Approximately two thirds of Contacts received these three facets of information as part of their counseling. It is noteworthy that approximately 70% of Physicians reported that they do provide information for these three elements during pre-test counseling.

Table 4: Pre-test Counseling Elements Pertaining to HIV Reporting

	Proportion of Index Cases stating they received this counseling n = 137	**Proportion of Contacts stating they received this counseling** n = 34	**Physicians reporting they routinely provide this counseling** n = 61
HIV is a reportable disease	51 (37%), (95% CI: 29%, 46%)	21 (62%), (95% CI: 44%, 78%)	42 (69%), (95% CI: 56%, 80%)
Non-nominal Option available	53 (39%), (95%CI: 31%, 47%)	22 (65%), (95% CI: 47%, 80%)	47 (77%), (95% CI: 65%, 87%)
PCRS recommended if index test is positive	70 (51%), (95% CI: 42%, 60%)	22 (65%), (95% CI: 47%, 80%)	46 (75%), (95% CI: 63%, 86%)

PROVISION AND QUALITY OF DATA

One of the purposes of HIV Reporting is to enhance epidemiological surveillance to facilitate planning and provision of HIV/AIDS programs and policies at a local and provincial level. Timeliness and availability of HIV data are key to planning and provision of services. A Case Report Form (CRF) was designed to capture surveillance information provided by reporting nurses and Physicians in each Health Authority. See Appendix 10. The HIV surveillance nurses at the BC Centre compile the results for Disease Control. This information is then made available to Health Authorities and policy makers.

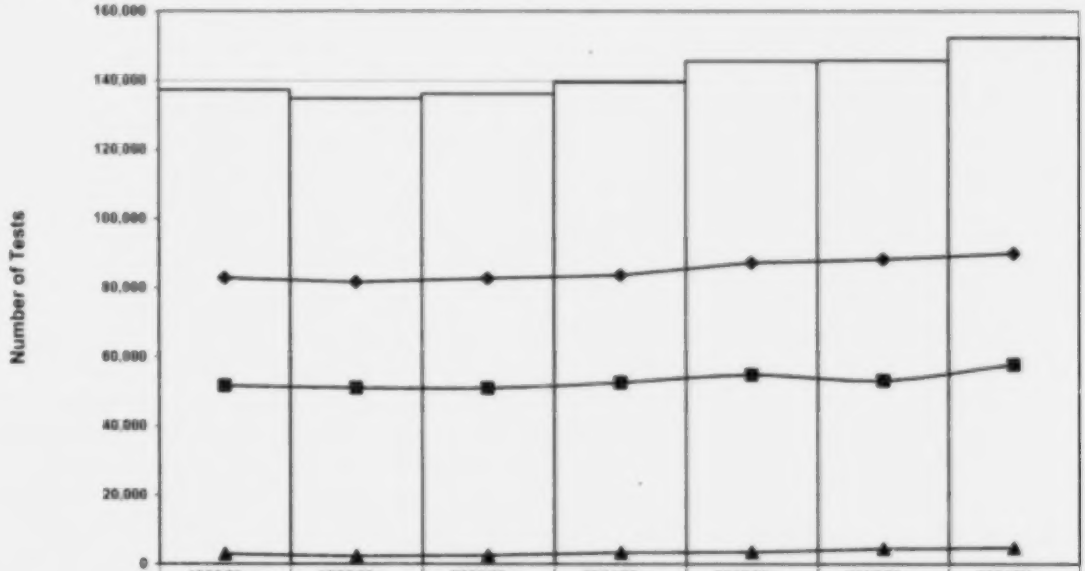
Overall, the amount of time to complete case management and the corresponding CRF has decreased over time. In the first year of Reporting the median number of weeks it took to complete the mandatory reporting documentation was 14.1 weeks (min: 0.6; max: 72.7). In the 3 months prior to the end of the evaluation period, the median time to complete the required documentation was significantly reduced to 4.14 weeks (min: 0.3; max: 10.1) ($p = <.001$, Mann-Whitney U test) indicating an improved efficiency in the documentation process.

When surveyed, 5 (55.6%) of the 9 MHO respondents who answered this question stated they received surveillance information in a timely or very timely fashion. Seven out of the 11 MHO respondents rated the quality of HIV data specific to their local Health Authority on a 5-point Likert scale. Five (71.4%) of the seven stated that the quality of the data was good or very good. All 11 MHO participants responded to the question "Do you analyze or review your local data on a regular basis?". Six (54.5%) stated they review the data on a regular basis, and an additional 2 (18%) stated their communicable disease team reviews it. How often they reviewed the data varied from monthly (2), to every three months (1), to annually (2). One respondent did not specify the frequency interval for reviewing the data.

Newly diagnosed HIV Cases and Willingness to Test

The number of HIV tests was stable in the first year after the onset of reporting and increased in the second year by 4.5% (from 145,873 to 152,440 tests). This increase continued the rising trend in HIV tests seen in the two year prior to HIV Reporting (4.4% and 2.5% respectively) However, these changing trends in HIV testing numbers are not statistically significant. Figure 1 shows the trend in the number of HIV tests before and after HIV Reporting by gender.

Figure 1: Number of HIV tests before and after mandatory HIV Reporting

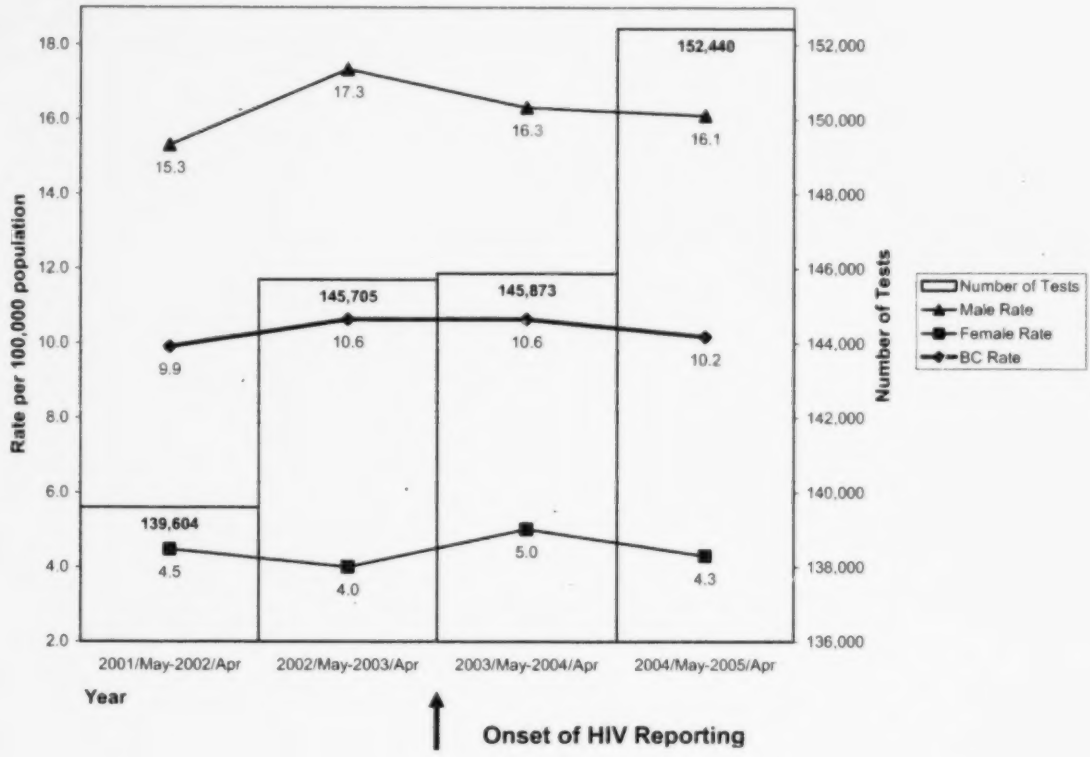


	1998/May-1999/Apr	1999/May-2000/Apr	2000/May-2001/Apr	2001/May-2002/Apr	2002/May-2003/Apr	2003/May-2004/Apr	2004/May-2005/Apr
Total	137,341	134,843	136,184	139,604	145,705	145,873	152,440
Female	82,846	81,615	82,699	83,657	87,317	88,275	89,945
Male	51,629	50,988	50,968	52,584	54,866	53,122	57,776
Unknown	2,866	2,240	2,517	3,363	3,522	4,476	4,719

It is noteworthy that the number of male tests decreased by 3.2% in the first year after reporting compared to a 1.1% increase in female tests in this time period. In the second year post reporting, male and female tests increased by 8.8% and 1.9% respectively over the previous year. It should be noted that there was a large increase in the number of unknown gender tests in the year after reporting. However, even if all these unknown tests are assumed to be male, there was still a 1.4% decrease in the number of male tests in the first year post reporting. Despite this decrease in male testing in the first year after mandatory HIV Reporting, this is not statistically significant when this is compared to the average annual change in HIV testing predating HIV Reporting (beginning May 1998).

The fluctuation in testing in the two years post reporting has not appeared to have had an impact on identifying positive cases. Between 1 May 2003 – 30 April 2005, 884 persons tested newly positive for HIV maintaining the trend in new cases seen prior to reporting. This is also reflected in the rate of newly diagnosed HIV positive persons per 100,000 population. This has not changed significantly for BC or for males or females when analyzed separately over the four year period preceding reporting and the two years since its onset. Figure 2 shows these HIV positive rates for BC by gender for the two year period preceding reporting and the two year period since its onset.

Figure 2: Number of HIV tests and rates of newly diagnosed HIV cases per 100,000 population before and after mandatory HIV Reporting



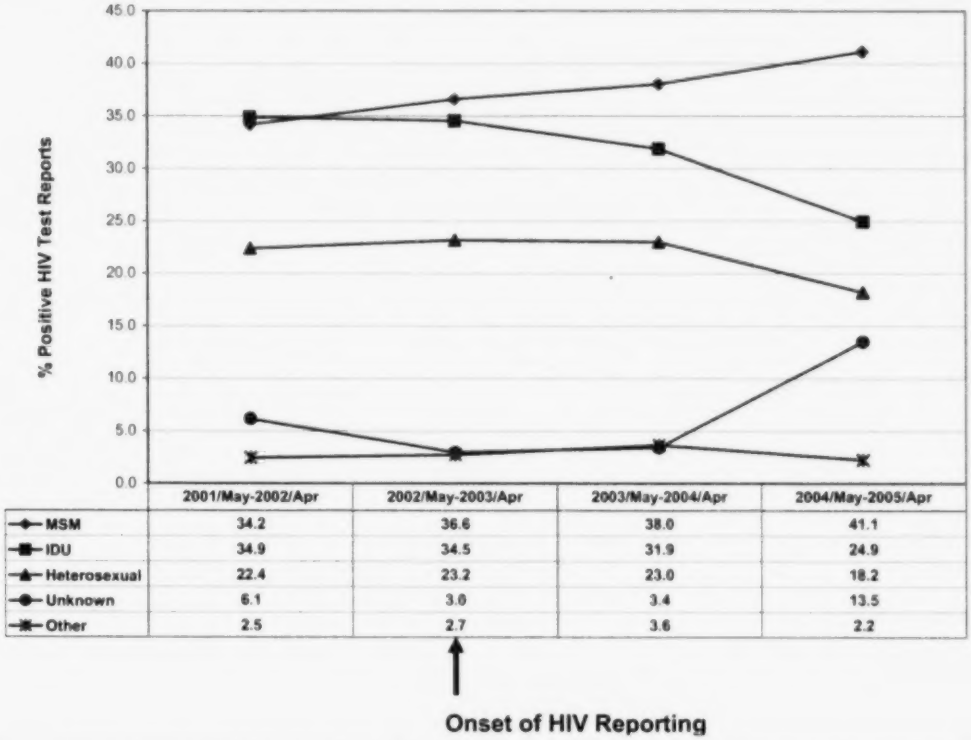
Reported HIV positive diagnoses were also examined by risk category from numerator data collected for these groupings. Unfortunately, rates of newly diagnosed HIV positive persons are not possible to compute for MSMs, IDUs, or heterosexuals as there is no accepted denominator data for these risk categories. When one looks at the number of positive tests by these groupings over these reporting periods one notes that the number of newly diagnosed MSM cases increased by 3.7% in the first year after reporting (161 to 167) compared to an increase of 15.8% the year before (139 to 161). In the second year post reporting the increase over the previous year was 9.6% (169 to 185). However, the average annual change in HIV positive MSMs as a proportion of all adult HIV positive results before and after HIV Reporting is not statistically significant.

Table 5 shows the number of newly diagnosed HIV positive cases by risk category for the two years preceding reporting and two years since its onset. Figure 3 shows these trends as a proportion of adult HIV test reports by risk category for these periods.

Table 5: Number of newly diagnosed HIV positive cases by risk category, May 2001-April 2005

	Number of Newly Diagnosed HIV Positive Cases			
Risk Category	**01 May - 02 Apr**	**02 May - 03 Apr**	**03 May - 04 Apr**	**04 May - 05 Apr**
MSM	139	161	167	183
IDU	142	152	140	111
Heterosexual	91	102	101	81
Unknown	25	13	15	60
Other	10	12	16	10
BC Total	**407**	**440**	**439**	**445**

Figure 3: Proportion of adult HIV test reports by risk category and by year of diagnosis

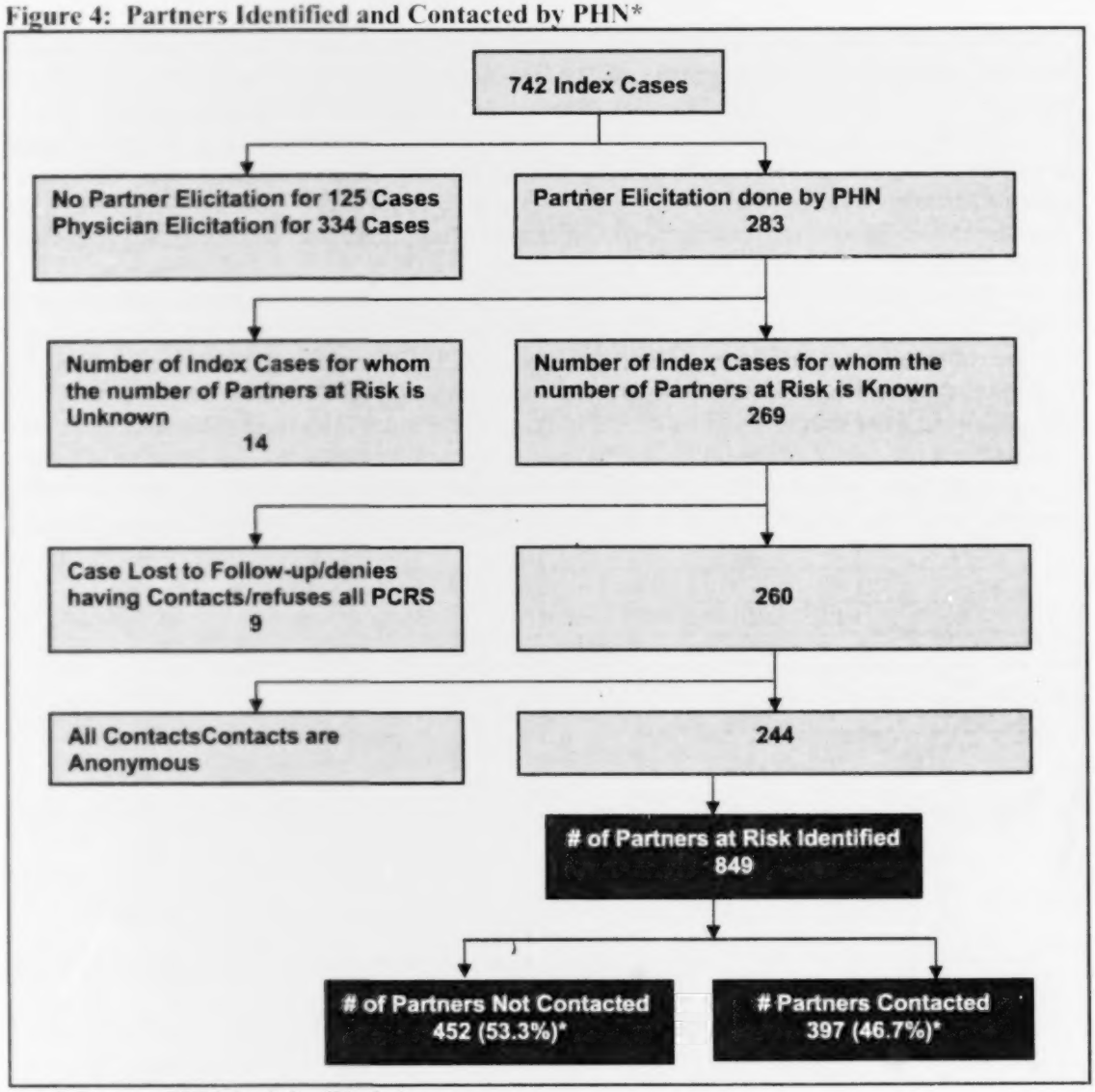


PARTNER COUNSELING AND REFERRAL SERVICES

As mentioned above, one of the goals of making HIV Reportable was to improve and facilitate PCRS. However, due to the lack of systematic collection of PCRS data prior to Reporting, we are unable to assess any change in PCRS as a result of Reporting. Therefore, only descriptive data for the evaluation period are presented. Index Cases, who responded to the question "How many people will you, your doctor or your PHN notify about their possible exposure to HIV?" reported a median of 2 Contacts per Index Case (range 1 – 20). Twenty-eight percent stated that they had no partners to be notified.

Partners identified and contacted by PHN: Among the 742 cases recorded on the PHN Activity Worksheet, 283 had partner elicitation done by a PHN. Among these, 14 (4.9%) were unaware of the number of partners at risk. An additional 23 (8%) refused PCRS, were lost to follow-up, died or denied sexual/drug partners, and a further 16 (5.6%) stated that all their Contacts were anonymous. The remaining 244 cases identified 849 partners. This amounts to 3.48 partners per case. Of these, 397 (46.7%) were successfully contacted. See Figure 4. This is similar to the 50% of partners that Physicians estimate are successfully contacted by them. PHNs reported contacting 36% of partners in the Vancouver area and 70% in the non-Vancouver areas.

Figure 4: Partners Identified and Contacted by PHN*


742 Index Cases
No Partner Elicitation for 125 Cases
Physician Elicitation for 334 Cases
Partner Elicitation done by PHN
283
Number of Index Cases for whom the number of Partners at Risk is Unknown
14
Number of Index Cases for whom the number of Partners at Risk is Known
269
Case Lost to Follow-up/denies having Contacts/refuses all PCRS
9
260
All ContactsContacts are Anonymous
244
# of Partners at Risk Identified
849
# of Partners Not Contacted
452 (53.3%)*
Partners Contacted
397 (46.7%)*

* Source: PHN Activity Worksheets

HIV Testing as a result of HIV Reporting: This was examined from the perspective of Contacts and Index Cases. For the latter, this was assessed from questionnaires administered to the Index Cases and an analysis of reasons for testing from data on all newly positive cases from the CRF.

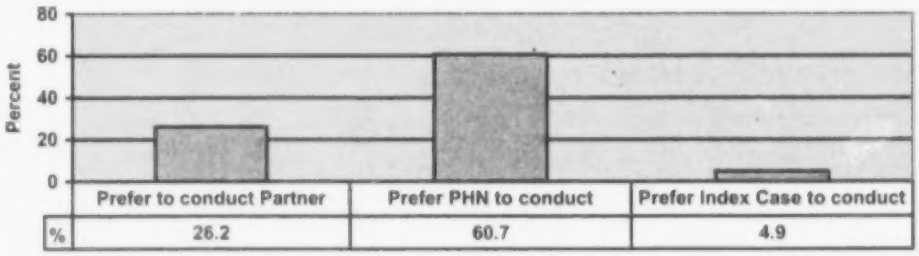
- A total of 27 (79.4%) of the 34 Contacts who completed a questionnaire stated they went for HIV testing as a result of being told they may have been exposed. This may be an overestimate of the testing behaviour of all Contacts as most of these respondents were interviewed by healthcare providers and PHNs during their contact with the health care system. In order to determine whether people were being screened for HIV as a result of the enhanced contact tracing efforts associated with HIV Reporting, Contacts were asked if they were told of possible exposure to HIV by a doctor, PHN or someone else. Ten (29.4%) Contacts stated they were informed by a doctor and 9 (26.5%) stated they were informed by a PHN of this possibility.
- Index Cases who completed a questionnaire, were asked to provide the main reason they went for a HIV test. Among the 137 respondents, 14 (10.2%) stated they went for a test because someone told them they may have been exposed. The "someone" in this question does not specify healthcare provider versus a partner or someone they knew. The most common reasons cited for being tested included being worried about possible exposure (23.4%), engaging in risk behaviours (11.7%), and suspicion of symptoms of HIV (10.9%).
- Table 6 describes the main reason for testing noted by the health care provider or PHN on the CRF. Among the 884newly positive cases, "Notified as a contact" was listed as the main reason for testing in only 35 (4%) of cases. This suggests that those Index Cases that completed a questionnaire tended to be ones for whom partner notification assumed a more important reason for testing.

Table 6: Main reason for testing since reporting (1 May 2003 – 30 Apr 05) as recorded on Case Report Forms (n=884)

Reason for Testing	Number (%)	Reason for Testing	Number (%)
Patient requested a test	201 (22.7%)	VISA requirement	17 (1.9%)
History of known risk factor	142 (16.1%)	Prenatal workshop	16 (1.8%)
Symptomatic – early/late HIV/AIDS	94 (10.6%)	Research study requirement	12 (1.4%)
Symptomatic – seroconversion	67 (7.6%)	Immigration requirement	4 (0.5%)
Partner of an HIV positive person	57 (6.4%)	Organ/blood donor program	0
Notified as a contact	35 (4.0%)	Other	58 (6.6%)
Confirmatory test	28 (3.2%)	Unknown/unspecified	78 (8.8%)
From country where HIV is endemic	18 (2.0%)		

Physician preference for PCRS: Figure 5 displays physician preferences regarding who should conduct PCRS. The majority of Physicians stated they prefer to have a PHN undertake these activities.

Figure 5: Physician reported preferences for conducting PCRS



The non-nominal reporting option has raised some issues for Physicians. Concern was expressed about taking responsibility for trying to deliver a result to the correct person if they test without their correct, full name. This is similar to the concern raised by some directors of private laboratories in BC. In addition, many physician offices and clinics cannot accommodate non-nominal file management and non-nominal option is impossible in acute care settings.

Incidents of Harm

Data pertaining to incidents of harm were captured from Critical Incident Forms (CIF) created for PHN and primary health care providers to report incidents of harm experienced by their clients. See Appendix 11. In addition, Index Cases, partners, PHN, and Physicians were asked, in their evaluation questionnaire if they were harmed in any way as a direct result of reporting. Community agencies and MHOs were also asked if they had knowledge of any clients being harmed as a result of HIV Reporting.

A total of 4 Critical Incident Forms were received one of which did not contain a true critical incident. In addition, 49 Index Cases, and 6 Contacts indicated in their questionnaires that they experienced harm as a result of HIV becoming reportable. After reviewing the data, it became evident that people reporting incidents of harm did not differentiate between harm as a result of becoming HIV positive and harm as a direct result of Reporting. For example, one person said they were emotionally harmed by HIV becoming reportable because they experienced depression as a result of the new diagnosis. A committee of 4 consisting of three authors of this report (DT, LK, DS) and an HIV surveillance nurse (CW), reviewed each report of harm and differentiated between incidents that were definitely a result of HIV becoming reportable; possibly a result of HIV becoming reportable; or those felt not to be a result of HIV becoming reportable. Incidents that were considered to have occurred independent of Reporting were classified as "not a result of HIV becoming reportable". Incidents that were felt to be the result of public health involvement were classified as "definitely a result of HIV becoming reportable", and incidents for which little or no details were provided were considered "possibly a result of HIV becoming reportable".

All reported Critical Incidents were assigned to one or more of the categories of physical harm; emotional harm; shunned by community; loss of job; and various forms of disclosure. A breakdown of reported Critical Incidents is shown in Table 7.

- One instance of emotional harm and three additional instances of third party disclosure from a PHN office were felt to have occurred to four Index Cases.
- Nineteen Index Cases and four Contacts possibly suffered harm as a result of HIV becoming reportable but this was not substantiated with details.
- Thirty nine Index Cases and seven Contacts were felt to have suffered consequences of their HIV testing experience but this was not considered to be a result of HIV becoming reportable.

Table 7: Number of Reports of Harm collected from Critical Incident Forms and Evaluation Index Case and Contact Evaluation Questionnaires

Nature of Harm	Not a result of HIV becoming reportable	Possibly a result of HIV becoming reportable, but not substantiated with details	Definite result of HIV becoming reportable.
Physical harm		Index: 2 Contact: 1	
Emotional harm	Index: 8 Contact: 2	Index: 8 Contact: 2	Index: 1
Shunned by community		Index: 7	
Loss of job		Index: 2 Contact: 1	
3rd party disclosure from MD office	Index Case: 3 Contact: 1		
3rd party disclosure occurring from PHN office			Index: 3
3rd party disclosure occurring in community	Index Case: 28 Contact: 4		
Total	**46**	**23**	**4**

Among the CIFs completed, one involved a breach of Index Case confidentiality. A third party counselor, not trained in partner counselling, informed the Index Cases partner that the HIV PHN nurse was looking for him. From this, the partner was able to deduce the identity of the newly positive Index Case. The counselor was instructed about the inappropriateness of this action. A second incident involved verbal violence directed at a PHN when she visited a contact to inform him he may have been exposed to HIV. The PHN discussed this incident with STD Control and her manager. No other action was taken. The third incident report also involved a harm or threat to the public health nurse from a case. The case accused the PHN of disclosing his identity to the contact in a very angry and distressing manner. In actual fact, it was the Index Case's family physician that breached this confidentiality. The PHN was referred to her family physician to deal with the resulting anxiety resulting from the incident.

There were no reports of harm experienced by participating Physicians as a result of reporting. It should be noted that the potential of harm to health care workers as a result of reporting communicable diseases is not unique to HIV. One PHN stated that she had not been harmed by HIV Reporting but had received threats of harm from Chlamydia reporting.

Two Physicians reported having knowledge of one incident of breach of confidentiality (non-nominal case called out to PHN nominally) and one incident of physical abuse experienced by an Index Case from her partner. It is unclear from the report if this abuse was the result of PCRS conducted by public health, or abuse that may have occurred even if HIV were not reportable. The physician who wrote about this incident in their evaluation questionnaire did not complete a CIF.

Community agencies were asked open-ended questions about their knowledge of incidents of harm among their clients. Nine (7%) of the community agency workers stated they were aware of harm. When asked to specify, the agencies provided general comments about groups of people being discriminated against, stigmatized, experiencing disruption to family relationships, and receiving threats of assault. Once again, insufficient detail was provided to be able to differentiate between harms as a result of people being HIV and harms that could be attributed directly to HIV Reporting. Aside from incidents of direct harm, 5 (16.6%) of the community agencies that completed the evaluation survey reported knowledge of people not going for testing due to fear of breach of confidentiality that may have been associated with HIV Reporting. These agencies represent IDUs(1), all persons with HIV/Hepatitis C in a rural area of BC(1), and Aboriginal communities (3).

Impact on Resources

Personnel: At the beginning of HIV Reporting, each HSDA in BC designated one PHN from their communicable disease team and one alternate PHN to the HIV Reporting process. The only exception was Vancouver, who designated 2 PHNs It was expected that the non-Vancouver nurses would conduct HIV Reporting duties in addition to their existing workload. No additional funding was provided to these HSDA's and therefore the cost of the reporting process was initially absorbed by their existing budget. In the fall of 2004, the Provincial Health Officer provided financial resources to each Health Authority based on the number of cases in each area in response to a request from public health nursing for increased nursing resources to do HIV Reporting work and for increased funding for their educational support and training. This resulted in the equivalent of 1 FTE for each Health Authority with the exception of Vancouver and Fraser Health Authority who received the financial equivalent of 3 FTE and 2 FTE positions, respectively.

Time spent per case: The number of PHN nursing hours expended upon HIV Reporting per case was documented on the PHN Activity Worksheet and also determined from information obtained from the Public Health Nurses questionnaire. The mean number of hours spent per HIV case from the Worksheet was 3.5 hours (range: 30 min – 112 hours). However, when only cases for which the PHN conducted all the follow-up activities were considered the mean number of hours spent per HIV case was 6.7 hours (range: 30 min – 112 hours).

On their questionnaires, PHNs estimated time spent per case as follows: correspondence with health care providers (mean 1 hr per case; range: 30 mins – 2.5 hours); visits or phone calls with Index Cases (mean 2 hrs; range 30 min – 20 hours); and completion of forms (mean 1.7 hrs; range 30 min – 4 hours). PHNs estimated that a further 4.3 hours per case (30 min – 12 hours) were spent on miscellaneous documentation, communication with the community and other PHNs, travel and professional development. A majority of PHNs initially stated that they were overwhelmed by the amount of paperwork involved in the reporting process. In response to this feed back, mandatory reporting forms were shortened. It was also clear from the data that issues around the non-nominal option consumed a large amount of time for PHNs and HIV surveillance nurses. Requisitions from more than half of the positive HIV tests did not indicate whether the test was nominal or non-nominal. According to the HIV surveillance nurses and PHNs, large amounts of time were spent determining the nominal or non-nominal nature of the tests and communicating with Physicians about the fact that they had a patient in their care that was HIV positive but was without a name. A computerized system was subsequently generated for BC laboratories that prompt clinicians ordering the test to provide the nominal/non-nominal status of the test to save time. When clinicians fail to respond to the prompt, any test submitted with a full name but without a nominal option indicated must be called out as a non-nominal option by the HIV surveillance nurse.

Community Agencies: It was anticipated that community agencies servicing HIV positive people would use some of their resources responding to questions or concerns about Reporting from Index Cases and/or partners. Among the 30 community agency personnel who responded to the questionnaire, 8 (27%) stated that at least some of their clients have been asking them about HIV Reporting. Generally, agencies are receiving questions about the PCRS and specifically issues of confidentiality.

Economic aspects: This evaluation has not collected the necessary data to cost this new intervention. What is clear is that services have been stretched to implement the non-nominal option and that additional resources will be required to ensure that this option is available throughout the health care system. We have also not been able to assess the cost benefit or effectiveness of this intervention. This would require, among other data, knowledge of how many new cases of HIV, if any, were averted due to HIV Reporting.

Perceived Benefit or Detriment of Public Health Involvement in Case Management

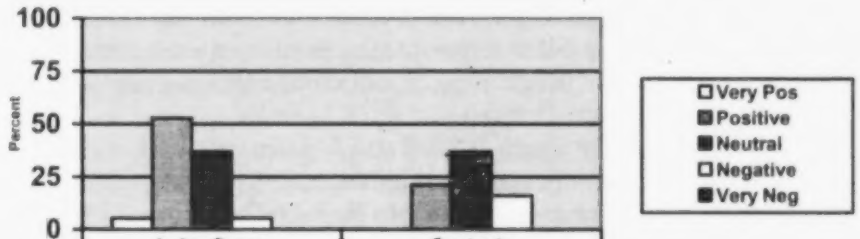
Approximately 73% of PHNs stated they felt that their calls to Index Cases improved the management of their health. Comments by PHNs also indicated that their involvement provided opportunities to assist newly HIV positive cases by connecting them to community resources sooner.

Among the 61 Physicians who completed an evaluation questionnaire at 24 months post-reporting, 40 (67.8%) stated they felt positive about public health involvement in HIV follow-up and PCRS. As mentioned above, the majority of Physicians (60.7%) prefer public health to do PCRS while 16 (26.2%) stated they prefer to do it themselves.

PHN, Physicians, Index Cases and Contacts were asked to rate their impression of public health involvement in case management using a five point Likert scale. Provision was also made for participants to include additional comments related to PHN involvement.

Primary Health Care Nurses: Figure 6 illustrates the perceptions of PHNs, at 24 months post-reporting, as to the receptiveness of their involvement in case management by Index Cases and Contacts. According to the PHNs, Index Cases tended to be more positive than Contacts. While neither Cases nor Contacts were felt to be very negative towards PHN involvement, 15.8% of Contacts were negative vs 5.3% of Cases. Likewise, 52.7% of Cases were positive vs 21.1% of Contacts.

Figure 6: PHN rating of receptiveness of Index Cases and Contacts to public health involvement in case management as collected on a 5 point Likert Scale



	Index Cases	Contacts
Very Pos	5.3	0
Positive	52.7	21.1
Neutral	36.8	36.8
Negative	5.3	15.8
Very Neg	0	0

Index Cases and Contacts: Overall, 63 (45.8%) Index Cases surveyed agreed or strongly agreed that their experience with HIV Reporting was positive compared to 22 (64.6%) of Contacts. However, 30(21.7%) of Cases and 10(29.4%) of Contacts disagreed or strongly disagreed that this was the case. Cases and Contacts were also asked about the usefulness of PHN and physician visits or calls. These data are shown in Table 8. The majority of both Index Cases and Contacts agreed or strongly agreed that PHN and Physician visits were useful in managing their health although Index Cases felt most strongly about this.

Table 8: Rating of Index Cases and Contact's reaction to PHN and Physician visits or calls as collected on a 5 point Likert scale

		PHN visits useful in managing my health	Physician visits useful in managing my health
Index Case	Agree or Strongly Agree	74 (82.5%)	99 (72.2%)
	Neutral	20 (14.6%)	16 (11.7%)
	Disagree of Strongly Disagree	10 (7.2%)	12 (9.1%)
	Not applicable	25 (18.2%)	5 (3.6%)
	No response	8 (5.8%)	5 (3.6%)
Contacts	Agree or Strongly Agree	21 (61.8%)	20 (58.8%)
	Neutral	4 (11.8%)	3 (8.8%)
	Disagree of Strongly Disagree	4 (11.8%)	4 (11.8%)
	Not applicable	3 (8.8%)	5 (14.7%)
	No response	2 (5.9%)	2 (5.9%)

Impact on Health Care Services to HIV Positive People

In order to determine the impact of HIV Reporting on health care services for HIV positive people, MHOs were asked to describe any new or improved services that were implemented as a result of information provided from HIV case reporting. They were asked to specify new efforts to plan, develop and implement local HIV/AIDS programs and support services in the past two years as a result of the data they received. Out of the 11 MHO respondents, one new program was reported, in the Fraser Health Region, in which the need to provide case support in Punjabi was identified. This was a result of PHNs recognizing an increase in HIV positive non-English speaking Indo-Canadian clients. Three other MHOs stated that the data has been used to plan, develop and implement programs and support services but the specifics of these programs were not provided. One MHO stated that the data is presented as part of multidisciplinary meetings to identify gaps in services for their local area.

PHNs and Index Cases were asked about their impression of the support services in their health service delivery area. PHNs reported that the services in larger areas (e.g. Vancouver, Richmond) were satisfactory, but services in smaller communities were minimal or absent forcing clients to travel to receive services. This opinion did not change between the 7 month questionnaire and the 24 month questionnaire. When asked, 90 (65.7%) of Index Cases stated they were satisfied with the HIV community referrals offered by their public health nurse or doctor.

Designated PHNs reported that they monitored HIV data subsequent to reporting and were able to notice trends (e.g. most cases coming from bath houses or massage parlours). From these trends they were able to tailor outreach programs.

PHNs designated to HIV Reporting mentioned being asked to sit on committees that enabled them to advocate for HIV positive people and lobby for funding. In particular, PHNs from the Fraser Health Authority have contributed to obtaining two federal grants aimed at providing HIV counselling specific to youth and the Indo-Canadian community. A third grant was also obtained enabling them to implement an adaptation of a "lounge" model that provides support to people with HIV.

Community agencies were asked about the benefits of Reporting and what could be done to improve the process. Responses to these open-ended questions included comments that Reporting can result in early support after diagnosis and increased awareness about HIV in communities. However, these agencies stated they would like to see increased education among health care professionals and more educational programs in communities aimed at prevention and to alleviate fears of breach of confidentiality from the HIV Reporting process.

DISCUSSION

IMPACTS OF HIV REPORTING ON HIV TESTING

A key question has been to assess the potential impact of reporting on testing behaviour and patterns in BC. Attempts to interpret HIV testing data for this purpose are subject to possible confounding from prevention interventions and/or changes in risk behaviour. A further dimension that may offset positive impacts of reporting on HIV testing is that deferring testing could delay access to HIV treatment including antiretrovirals which could reduce infectiousness. Additional biases that may confound any interpretations include the possibility of duplicate tests and the lack of completeness of identifying information that accompanies HIV testing data.

With these limitations in mind, the HIV testing data demonstrate an overall increase in the number of tests in the first two years of HIV Reporting continuing a trend observed prior to this practice. The average annual increase in the number of tests in the 3 years prior to reporting was 2.6% and in the two years post reporting this was 2.3%. This suggests that the introduction of reporting has not deterred people from testing in the province overall. Alberta reported a similar experience in testing trends before and after HIV Reporting was instituted in this province in April 1998.[42]

However, the BC testing data show a plateau in the number of tests in the first year post reporting where the percentage increase over the year before was only 0.1%. As mentioned previously, this was mostly due to a reduction in the number of male HIV tests in the first year post reporting and was followed by a large increase the following year. Unfortunately, these general population data do not allow an assessment of a possible differential impact on testing behaviour in people who may be at higher risk of HIV infection.

Returning to the Alberta study, no such decrease was seen in males after the introduction of mandatory reporting. In fact the average annual increase in male tests increased significantly after this was introduced. The findings from the BC testing data may indicate that HIV Reporting had a transient impact on the overall number of tests being performed in the Province, especially on males.

As discussed, this has not been sustained suggesting that initial concerns about reporting expressed to the PHO during his consultations have probably been allayed and that it is likely that this public health practice is enjoying wider acceptance. Notwithstanding, some concerns may still exist and every effort should be made to continue sensitively describing this practice and the measures that have been taken to protect confidentiality and other harms to those presenting or being approached for testing.

The data suggest that reporting has not appeared to have impacted on the number of HIV diagnoses in the Province overall. The flat trend in identification of newly positive cases of HIV of approximately 10 per 100,000 population per year has continued since the introduction of this intervention. This plateau in the number of newly diagnosed HIV cases presents a reminder to the province of the need to escalate HIV prevention efforts if we are to achieve the goals set in the Provincial Strategy[43] of reducing the number of new infections by 50%.

While the overall rate of new infections reported has not changed for the population as a whole, this may mask changes in sub populations. Unfortunately, we were not able to assess trends in the rates of infections per 100,000 population per year for the various risk groupings given the lack of denominator data and the small sample sizes of HIV positive data from these vulnerable populations. However, when the trends in the number of MSMs testing positive and the proportion of adult HIV positive tests attributed to MSMs is reviewed there is a suggestion, albeit not statistically significant, that high risk MSMs may have marginally decreased their testing behaviour in the first year post reporting and reinstated this in the second year. If this did occur this might explain some of the fluctuations described in male testing in BC in the two years post reporting mentioned above. Altered testing behaviour in MSMs would not have been unexpected. MSMs and their representatives were vocal in their concerns about reporting and may have demonstrated these concerns by altering their testing behaviour. The data suggests that if there were concerns then these may have abated in the second year post reporting signaling a satisfaction with how mandatory HIV Reporting is being implemented. It is important to note that a targeted syphilis testing campaign channeled through Xtra West[iv] occurred during October 2003. This campaign may have resulted in MSMs increasing their requests for HIV testing and may account for the higher change in the number of HIV positive test results and proportion of positive test results attributed to MSMs in the second year post mandatory HIV Reporting. However, this remains an hypothesis.

The proportion of newly diagnosed IDUs decreased in the first year post reporting and decreased further in the second year. This continued the trend noted in the year preceding reporting and is in keeping with the decline, since 1999, in the proportion of adult HIV positive tests attributed to IDUs reported nationally[44] as well as the declining incidence rates from the Vancouver Injection Drug User Study (VIDUS)[45]. Our data do not allow us to dissect out what proportion of this decline in the number of newly diagnosed IDUs in BC may have been due to reporting. However, we are cognizant that this grouping may feel most vulnerable with respect to reporting and that special efforts should continue to allay fears of harm from this practice in this vulnerable population.

[iv] Founded in 1993, Xtra West, Vancouver's Gay & Lesbian Biweekly, is the largest and most widely read publication targeting Vancouver's gay community. Every two weeks 30,000 copies reach 54,000 readers. On line at: http://www.xtra.ca/public/main.aspx?AFF_TYPE=4

Pre-Test and Partner Counseling and Referral Services

It is widely suggested that pre-test counseling of Index Cases and PCRS is not adequately assured in the absence of specific public health staff involvement. In this context, a positive impact of reporting has been the involvement of Public Health in partner elicitation for approximately half of the newly positive cases providing a more consistent approach to case management. Overall, public health involvement in case management has been well received by Index Cases, Contacts and Physicians. Most Index Cases and Contacts found their visits with public health useful in managing their health with Index Cases feeling more strongly about this. However, when asked directly about experiences with reporting, one fifth of cases and one third of Contacts disagreed that this was positive. While these questionnaires were completed by a very low proportion of Index Cases and partners, these negative responses deserve more detailed follow up, possibly through in depth interviews, to define aspects of reporting that can be improved upon early on in the process.

Of concern are those Physicians that report not informing their patients that HIV is reportable, that testing non-nominally is an option, and that PCRS is recommended if an HIV test is returned positive. This concern is strengthened by the apparent discrepancy between the perceptions of Index Cases and Contacts of whether they have received information from Physicians about these issues and the extent to which Physicians report conveying this information. This may suggest that the Physicians are not succeeding in communicating these issues effectively to all the cases and Contacts that they counsel. One possible explanation for the omission by some Physicians to inform clients of a non-nominal option is their own relative discomfort with this given the demands this has on resources. Another possibility is volunteer bias, i.e. participants that did not receive the necessary pre-test information were more likely to complete a questionnaire. Notwithstanding these possible explanations, these three elements are critical pieces of information to be provided in the context of HIV Reporting. More attention needs to be given to closing this information gap possibly with the (better) use of written materials and greater team work between Physicians and those trained and mandated to provide HIV and related education and counseling. Physicians may also benefit from updates/training on counseling and check lists to remind them to raise key issues although prior consultation with Physicians and their College is important before developing any of these interventions.

Since no prior documentation exists on PCRS for HIV positive people and since historical comparison could not be conducted, no conclusion can be reached regarding whether HIV Reporting has improved or worsened contact tracing. Among the contactable partners, approximately half of them are actually being reached by public health, a physician or an Index Case. There is a concern about the proportion of cases that do not allow partner notification due to desires for anonymity, refusal to participate in partner elicitation and loss to follow-up. To add to this concern is the potential that, as reporting continues, the possibility exists that persons from vulnerable populations may increasingly identify partners as being anonymous to avoid their follow up. This is probably more likely for repeat testers and/or individuals engaged in high risk activities, in order to protect partners that allow them unprotected sexual encounters and a greater deal of intimacy. This suggests that particular attention should be given to those that identify anonymous partners. These individuals may require enhanced counseling to empower them to undertake self referral. In addition, these cases should be reminded of non-nominal testing and non-nominal reporting options for their partners so as to minimize barriers to partner notification.

It is worth noting that in a survey in the US of persons reported with AIDS, participants who had recognized their HIV risk and sought testing at anonymous testing sites reported entering care at an earlier stage of HIV disease than persons who were first tested in a confidential testing setting (e.g., STD clinics, medical clinics, or hospitals), where persons are frequently first tested when they become ill.[46] These findings support the importance of a non-nominal option for HIV Reporting as well as the provision of non-nominal testing in BC. It is encouraging that one study that assessed whether HIV-positive men who seek confidential versus anonymous HIV counseling differed with respect to agreement to partner notification found no difference indicating that those who elected for anonymous counseling still tended to notify their partners to come forward for testing.[47] Ultimately, however, improvements in persuading cases to bring partners into the health care system depend to a great extent on their own experiences with the system. These enhanced approaches are akin to those offered as part of Prevention Case Management[48] and provide challenges for providing the skill base within the services to achieve optimum partner notification rates.

A greater percentage of notifiable partners were contacted in areas outside Vancouver. This may be because in these areas the Public Health Nurses have established relationships in the community and are involved with their community for TB clinics, immunization clinics, baby clinics etc. Therefore, a relationship of trust may already be established with Index Cases and their partners possibly resulting in less stigma attached to PCRS activities. An additional reason may be that Vancouver has greater numbers of MSM and sex workers who, due to the number of partners and desire for anonymity, are less able to provide sufficient information to identify partners.

HARMS

Reports of harm as a result of HIV becoming reportable should be interpreted with caution. Questions related to incidents of harm on the evaluation questionnaires seemed to provide an opportunity for Index Cases and Contacts to express their fears about confidentiality and to express the feelings about stigmatization related to being HIV positive. For this reason, it is difficult to differentiate between harms that resulted because HIV was reportable and harms that would have happened irregardless of HIV being reportable. This is particularly true of the small number of reports of physical harm. HIV Reporting has possibly put a new spotlight on the potential of harm to Index Cases as a result of partner notification and highlighted the importance of domestic violence screening as an element in the counseling of Index Cases before any form of PCRS can be initiated.

There were several reports of breaches of confidentiality. Most of these involved disclosure of a cases' HIV status to a third party. The source of these disclosures was mainly friends and relatives of the Index Cases. Once again, it is likely that this disclosure would have happened regardless of HIV being reportable. However, there were a small number of reports of breach of confidentiality stemming from a Physicians office or a public health office. These reports, especially the ones from a public health office, can most likely be attributed to HIV becoming reportable. Initiatives are required to reinforce the importance of health workers maintaining confidentiality.

LIMITATIONS

This report provides limited information from Index Cases and from Contacts. Attempts to recruit Index Cases at the same time that they were given their HIV positive result may have acted as a barrier to survey acceptance. As a result, there is a strong likelihood of volunteer bias within the Index Case and Contact respondents. It is possible that participants who felt positively about HIV Reporting may have been more willing to participate in the evaluation. In addition, the Index Cases and Contacts who participated in the evaluation were significantly different in gender and ethnicity than the total population of newly positive HIV people in BC during the same time period. Therefore the opinions from the Index Cases and Contacts who did complete surveys may not be representative of all people who became newly HIV positive between 1 May 2003 and 30 Sept 2005.

CONCLUSION AND RECOMMENDATIONS

This evaluation of HIV Reporting in BC has fulfilled the obligations of the PHO to undertake an early assessment of this new public health practice. Overall, the conclusions reached from examining the various data collected during this evaluation support the continuation of this intervention and legitimize public health involvement in the process of HIV care and prevention.

However, the evaluation highlights areas of improvement to optimize this surveillance activity and the potential benefits it has for HIV prevention and control. All stakeholders in this process have a role to play. The evaluation also highlights further research to increase our understanding of how HIV Reporting can best be integrated into a holistic response to the epidemic.

1. Feedback Evaluation Results to Stakeholders

The spirit behind the introduction of mandatory HIV Reporting has been a consultative one. The evaluation continued this approach by attempting to reach out to the full spectrum of stakeholders who were or could be impacted by this intervention. Appropriate feedback of the findings of this evaluation should follow using existing forums as much as possible to help locate the evaluation in context and lay the basis for the implementation of recommendations for improvement. Communicating the evaluation will help sustain an ongoing dialogue to enhance this surveillance practice and help realize its benefits as well as support consistent messaging about this activity. Special attention should be given to those vulnerable populations that may have felt most impacted by HIV Reporting. It is suggested that organizations representing MSMs may be a priority in this regard but this does not exclude other vulnerable populations. In reaching out to all stakeholders, it is important to situate a discussion of HIV Reporting within the provincial strategic HIV/AIDS response framework of improving knowledge of sero-status especially in vulnerable populations and linking this knowledge to enhanced prevention initiatives and timely treatment, care and support.

2. Improve management of the non-nominal HIV Reporting option

This evaluation has emphasized ongoing problems with the implementation of the non-nominal option. Improved management of this option requires ongoing provision of information to the public regarding this option as part of the mandatory HIV Reporting process; successful elicitation of a decision on how an HIV positive test will be reported from the person being tested; and communication from the care provider through the blood drawing laboratory to the processing laboratory without compromise to a non-nominal choice. It is recommended that communications supporting HIV testing be reviewed and amended, if needed, to support an HIV Reporting choice (see recommendation 3); that Physicians receive reminders and continuing medical education about this; and that blood drawing laboratories do not proceed with obtaining a blood specimen for HIV testing unless a choice has been communicated to them by the care giver. In instances where care givers have failed to do this, it is recommended that blood drawing laboratories either refer patients back to their care givers or offer clients undergoing testing an option to read and sign a form indicating their understanding of this option and their preference for a reporting option. In this instance, it is also recommended that the blood drawing laboratory provide the referring care giver with a copy of this preference.

3. Community Health Worker to support PHNs

This evaluation indicates that PHNs may soon become over-extended with HIV case management. Efforts have already been made to reduce the time-consuming paper work. Thus, it is likely that they will require additional support. This could be met, in part, by a recent proposal for a pilot study in two Health Authorities (NH and FH) in which a Community Health Worker will work with the public health nursing team to provide support and education to selected clients with chronic diseases, including HIV. It is recommended that this pilot study be supported.

4. Emphasize choice and options

Individuals considering and being referred for HIV testing should appreciate that HIV Reporting occurs within a framework of choice regarding how one accesses HIV testing through non-nominal testing or nominal confidential testing sites; the option of nominal or non-nominal reporting; and the choice to have a PHN involved in follow-up management. Various communications, utilizing small and mass media as well as the Internet, have been produced to profile and support HIV testing. It is recommended that these be reviewed and appropriate information concerning these choices asserted within the context of reporting. In order to efficiently guide the revisions to the myriad of communiqués put out by various organizations it is recommended that the BCCDC and the health authorities, working with community organizations, summarize the issues that can be integrated into these various communications. A frequently asked question (FAQ) approach is probably the most efficient one to consider for this purpose.

5. Protect confidentiality

Community agencies expressed a concern that some of their clients fear being tested due to lack of understanding about how confidentiality is protected during HIV Reporting. Community agencies identified a need for increased public education and education directed at health care providers regarding the HIV Reporting process including information about how confidentiality is protected. In addition, education to health care providers should be conducted to communicate best practices regarding maintaining patient confidentiality. To these suggestions from the community agencies one should add education and reassurance for the agencies themselves so that they can inform their clients of measures being taken to protect this confidentiality. These discussions with the agencies should be part of an initiative to strengthen collaborations with public health in order to enhance the benefits of HIV Reporting.

6. Continue the use of the Critical Incident Form

Ongoing monitoring of potential harms as a result of mandatory HIV Reporting is important. This will continue to provide alerts to those implementing the process and highlight areas of possible improvement. It will also help to reassure stakeholders that public health is committed to ongoing quality improvement in the system. The Critical Incident Form has proved to be a useful tool during this evaluation for monitoring potential harms as a result of HIV Reporting and it is recommended that this continue to be used for this purpose.

7. Integrate domestic violence screening

Counselors are presently trained to include domestic violence issues within their approach but this is not done systematically using a tool to explore for domestic violence vulnerability. It is recommended that such a tool is developed together with a protocol defining what steps will be taken if a person is found to be vulnerable to HIV serostatus disclosure-related violence. Such a tool and protocol will compliment current discussions about developing guidelines for difficult HIV cases including, but not restricted to, those who are vulnerable to and who have suffered domestic violence.

8. Continued physician and PHN collaboration

Cases that were engaged by PHNs for their follow-up and who completed questionnaires were generally pleased with this case management. While this conclusion suffers from the same problem of generalizability already mentioned it does suggest that these services should be extended. This will require improved PHN/physician collaboration so that clients can be more strongly motivated to allow PHNs to provide this service. This will depend on improved communication between PHNs and Physicians regarding the benefits of public health involvement.

9. Enhance physician participation

Physician participation is critical to the HIV Reporting process and efforts should be considered to enhance their role and contribution towards improving the implementation of this mandatory surveillance activity. It is recommended that the College of Physicians and Surgeons and a representative sample of Physicians be interviewed to appreciate their information and other needs to realize this increased support including obtaining recommendations on how to best provide essential counseling elements related to HIV Reporting.

10. Ongoing research of index patients and Contacts

It has been emphasized that this evaluation has suffered from a likely lack of representativeness regarding data collected from cases and Contacts concerning their experiences with HIV Reporting. Yet, the few cases and Contacts that did indicate their lack of satisfaction with the process highlight the need to investigate this further. It is recommended that qualitative research approaches be considered for this so that issues raised can be explored in more detail.

11. Monitor HIV testing trends

The one data source that is most representative and has the sample size to assess meaningful trends in relation to the onset of reporting is the number of people testing for HIV. The early trends that have been presented should be monitored to ensure that any apparent downturn in the number of people testing in the first year of reporting maintains the regained momenturm achieved in the second year post reporting.

12. Assess medium and long term impacts of HIV Reporting on service provision

The time period covered in this evaluation is too early to detect the true effect on services to HIV positive people as a result of HIV Reporting. Future research should monitor and assess the services provided by public health for this patient population and specifically determine whether HIV infected persons are being referred to treatment centres earlier; if these clients are more prepared when they arrive at a treatment centre; and whether support groups are being accessed more frequently. This should also include surveys of MHO's and MHOs, PHNs to gauge their assessment of the impact of HIV Reporting on services.

ADDENDUM: Additional Information Collected From Public Health Nurses

PHNs were given opportunities to provide the evaluation team with additional information about Reporting through one-to-one interviewing and group discussions. The information gathered by these means was not included in the above report because we felt it would provided an over representation of PHN input. However, the material collected provides important anecdotal information about HIV Reporting from the PHNs perspective.

Advocacy Role

PHNs have expressed that, over time, their role of HIV Reporting nurse developed to include an important role as advocate on behalf of newly diagnosed HIV clients. This is especially true in smaller communities. Their experience with managing new cases, in collaboration with health care providers, was that the newly positive HIV individuals they were involved with needed assistance with maneuvering their way through the complex steps required to get HIV care. PHNs found themselves adopting an advocacy role, on behalf of their clients, which involved assisting with communicating with Physicians, completing social assistance paperwork and getting connected to support agencies.

Navigation Role

The PHNs worked together with the client and health care provider to help "figure out the system". As a result, PHNs felt that their clients were referred to services early and were well prepared when they arrived at service agencies. PHNs also felt they were able to share information regarding HIV services with Physicians who had little or no experience with HIV clients. This role is similar to that of 'patient navigation' found in areas of chronic care, especially for persons with cancer.[49] It involves expediting access to service and resources and improving continuity and coordination throughout a disease trajectory. PHSA is currently exploring the application of this concept to chronic disease management.[50]

PHN as Expert

Over time, some PHNs became viewed, by people in their communities, as experts in HIV and HIV Reporting. For example, when an HIV positive woman went into hospital to deliver a baby, the hospital nursing staff felt ill-equipped to care for this woman in a manner that would reduce transmission risk for the baby, the hospital staff, and other hospital patients. The PHN designated to HIV Reporting was brought into this situation to assist the hospital staff. PHNs felt that their role in HIV Reporting in their communities has raised awareness about HIV and has provided community education opportunities.

PHN-Client Relationships.

PHNs reported that nurse-client relationships that were established out of non-HIV related visits to the public health department paved the way for case management when the client became positive. Previously established relationships with newly positive clients may be a factor that contributed to the larger proportion of partners actually notified in the non-Vancouver areas. Similarly, PHNs stated that the relationships that were a result of HIV case management often lead clients returning to the health department for other reasons.

In some cases, the title of "HIV Reporting nurse" may act as a barrier when people in communities know the purpose of the nurses contact. Conversely, PHNs felt that some newly positive HIV clients were reassured about the fact that the HIV nurse was someone they knew they could talk to that would be stigmatize them.

Designated Time

The dedication of Public Health Nursing to HIV Reporting means they are able to devote significant amounts of time supporting HIV positive patients. This relieves pressure for the primary health care providers. As mentioned in the report, the amount of time spent managing a case of HIV (providing support to the case, contact tracing, etc) can range from 30 minutes to 112 hours. This may not be feasible for some health care providers. In some circumstances, nurses go out onto the streets looking for clients and their partners. The PHNs expressed that, in some cases, the large amounts of time spent on locating clients or their partners may have prevented some cases from missing follow-up due to "falling through the cracks".

APPENDICES

APPENDIX I: QUESTIONNAIRES FOR INDEX CASES

On May 1, 2003 HIV was added to the list of reportable diseases. This means that the Medical Health Officer in your health region must be made aware of your blood test results and efforts will be made to tell your partners or sexual Contacts that they may have been exposed to HIV.

Demographics

Gender
- ❑ Male
- ❑ Female
- ❑ Transgender
- ❑ Other _____

Age _____

Race:
- ❑ Caucasian
- ❑ Arab/West Asia
- ❑ Asian
- ❑ Black
- ❑ First Nations
- ❑ Hispanic
- ❑ Inuit
- ❑ Metis
- ❑ South Asian
- ❑ Other _____

Employment:
- ❑ Full time
- ❑ Part time
- ❑ Disability
- ❑ Unemployment
- ❑ Social Assistance
- ❑ Other _____

Yearly Household Income:
- ❑ Less than $10,000
- ❑ $10,000- under $30,000
- ❑ $30,000 – under $50,000
- ❑ $50,000 or greater
- ❑ I don't know

1. What is the main reason you went for an HIV test?
   - ❑ I was worried that I may have been exposed
   - ❑ Someone told me that I may have been exposed
   - ❑ I think I have symptoms
   - ❑ I engage in risk behaviours
   - ❑ I come from a country where many people are HIV positive
   - ❑ I have another STD (e.g. gonorrhea, syphilis, chlamydia, warts or herpes)
   - ❑ VISA requirement
   - ❑ Prenatal workup
   - ❑ Organ/blood donor program
   - ❑ Other (specify):_____

2. Who tested you?
   - ❑ My doctor
   - ❑ A Public Health Nurse
   - ❑ A community clinic
   - ❑ STD clinic
   - ❑ A street nurse
   - ❑ A private lab
   - ❑ Other (specify)_____

3. Where did you get your test done?
   - ❑ In the city or town where I currently live
   - ❑ I went to another community/town
   - ❑ Other (specify)_____

3. We would like to know how much information you received from the public health nurse or health care provider before you were tested for HIV. Please check the items below that the public health nurse or health care provider went over with you before testing you.
- ❑ HIV is now a reportable disease
- ❑ You can have the HIV test done with or without providing you name
- ❑ If you test positive for HIV, it is highly recommended that people who may have been exposed to your HIV should be contacted
- ❑ None of the above

4. Please indicate whether you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
Overall I have had a positive experience with HIV Reporting	1	2	3	4	5	6
Visits with my doctor have been useful in managing my health	1	2	3	4	5	6
Visits with my public health nurse have been useful in managing my health	1	2	3	4	5	6
I am satisfied with the HIV community services that I was offered by my public health nurse or doctor	1	2	3	4	5	6

5. **How many** people will you, your doctor, or your public health nurse notify about their possible exposure to your HIV? _____

6. Have you been harmed in any way as a result of HIV becoming reportable?
- ❑ yes
- ❑ no
- ❑ not sure

If yes, please check off all that apply:
- ❑ I have been physically harmed
- ❑ I have been emotionally harmed
- ❑ I have been shunned by my community
- ❑ I have lost my job
- ❑ I have not been harmed yet, but worry about being harmed
- ❑ Other (specify) _____

Please Describe Incident: _____

7. Have you experienced a breech of confidentiality (someone telling someone else about your positive HIV status) since your HIV test?
   - ❑ yes
   - ❑ no
   - ❑ not sure

   If yes, please check off all that apply:
   - ❑ Someone in my doctor's office told someone else about my HIV test result
   - ❑ Someone in the public health unit told someone else about my HIV test result
   - ❑ Someone other than me told someone else about my HIV test result
   - ❑ No one has told anyone yet, but I worry about this happening
   - ❑ Other (specify) _____

   _____

8. Please provide us with any other comments you may have regarding HIV becoming a reportable disease.

   _____

   _____

Would you be willing to be contacted in 6 months to complete this questionnaire again?
- ❑ no
- ❑ Yes If yes, please provide your name and phone number

APPENDIX 2: QUESTIONNAIRE FOR CONTACTS

On May 1, 2003 HIV was added to the list of reportable diseases. This means that the Medical Health Officer in your health region must be made aware of positive HIV blood test results and efforts will be made to inform people that they may have been exposed to HIV.

DATE: _____

Demographics

Gender
- ❑ Male
- ❑ Female
- ❑ Transgender
- ❑ Other_____

Age: _____

Race:
- ❑ Caucasian
- ❑ Arab/West Asia
- ❑ Asian
- ❑ Black
- ❑ First Nations
- ❑ Hispanic
- ❑ Inuit
- ❑ Metis
- ❑ South Asian
- ❑ Other _____

Employment:
- ❑ Full time
- ❑ Part time
- ❑ Disability
- ❑ Unemployment
- ❑ Social Assistance
- ❑ Other _____

Yearly Household Income:
- ❑ Less than $10,000
- ❑ $10,000- under $30,000
- ❑ $30,000 – under $50,000
- ❑ $50,000 or greater
- ❑ I don't know

1. Who told you that you may be at risk of having HIV?

- ❑ A doctor
- ❑ A public health nurse
- ❑ Someone else (specify) _____

2. Have you been tested for HIV as a result of being told you may have been exposed?

- ❑ yes
  If yes, did you leave the city/town you currently live in to be tested? _____
- ❑ no
  If no, please check why you haven't been tested for HIV yet?
  - ❑ I plan on being tested in the near future
  - ❑ I already know I have HIV
  - ❑ I simply do not want to be tested. Why _____
  - ❑ I don't know

3. If you were tested, we would like to know how much information you were given before you were tested for HIV. Please check the items below that you knew about before your test:

- ❑ HIV is now a reportable disease
- ❑ You can have the HIV test done with or without providing you name
- ❑ If your test shows you have HIV, people at risk of being exposed to your HIV will be contacted.
- ❑ None of the above
- ❑ I was not tested

4. When were you contacted by Public Health or your doctor about this issue

Date: _____ (YYY/MM/DD)

5. Please indicate whether you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
Overall I have had a positive experience with HIV Reporting	1	2	3	4	5	6
Contact with my doctor regarding my potential risk of HIV has been important and valuable to me.	1	2	3	4	5	6
Contact with my public health nurse regarding my potential risk of HIV has been important and valuable to me.	1	2	3	4	5	6

Please comment on anything completed above:

_____

_____

_____

6. Have you been harmed in any way as a result of HIV becoming reportable?
   - ❑ yes
   - ❑ no
   - ❑ not sure

If yes, please check off all that apply:
- ❑ I have been physically harmed
- ❑ I have been emotionally harmed
- ❑ I have been shunned by my community
- ❑ I have lost my job
- ❑ I have not been harmed yet, but worry about being harmed
- ❑ Other (specify) _____

Please Describe Incident: _____

Contact Questionnaire (Cont'd)

7. Have you experienced breech of confidentiality (someone telling someone else about you possibly being exposed to HIV) since your test?
   - ❑ yes
   - ❑ no
   - ❑ not sure

   If yes, please check off all that apply:
   - ❑ Someone in my doctor's office told someone else about my possible exposure to HIV
   - ❑ Someone in the public health unit told someone else about my possible exposure to HIV
   - ❑ Someone other than me told someone else about my possible exposure to HIV
   - ❑ No one has told anyone about my possible exposure to HIV yet, but I worry about this happening
   - ❑ Other (specify) _____

     _____

     _____

Would you be willing to be contacted in 6 months to complete this questionnaire again?
- ❑ no
- ❑ Yes If yes, please provide your name and phone number

APPENDIX 3: CASE REPORT FORM

Ethnicity: (see back) _____ Country of Birth: _____

Aboriginal: Yes □ No □ *If Aboriginal please indicate* (Metis □ First Nations □ Inuit □)

Health Care Provider
Ordering Test: _____ City: _____ HSDA: _____

Telephone: _____

Health Care Provider
For Follow-up: _____ City: _____ HSDA: _____

Telephone: _____

Client previously tested HIV positive? Yes □ No □ If yes, Date:_____ Province/Country : _____

Date blood sample drawn: _____ Date Reported: _____

Did Client Receive this Result: Yes □ No □ Date _____ From Whom: _____

Date of Most Recent Negative HIV Test: _____ None Found □

Please check all that apply (see back for explanation)

Health at Time of Test:

Seroconversion Illness □
Asymptomatic (early stage HIV) □
Symptomatic (later stage HIV) □
AIDS □
Unknown □
Current CD4 count _____
Current viral load _____

Risk Factors:

Heterosexual □
MSM □
Bisexual □
Partner of HIV+ person □
Sex Trade Worker □

Injection Drug User □
Blood or Blood Products □
Occupational Exposure □
Endemic Country □
Mother-to-Infant □
Other □

If other, describe _____

- If the client is in a facility (jail; hospital; treatment; other) please give details.

_____

- Are there any concerns re: violence related to the HIV Reporting Process? Yes □ No □ (If yes submit incident form.)
  Incident form submitted? Yes □ No □
- Has an 'Index Case Evaluation Questionnaire' been given to the client?
  Yes □ No □
- Has the client given consent for future BCCDC confidential contact for evaluation purposes?
  Yes □ No □

Contact method: _____

Form completed by: _____ Date: _____ Telephone #: _____

For Public Health Nurse to Complete

Date forms filed in local office: _____ Date forms sent to BCCDC: _____

APPENDIX 4: PHN ACTIVITY WORK SHEET

HSDA: _____

Case #	Date of Case	Forms completed by		Case Counseled by		Partner Elicitation done by		Total # of partners identified at risk	Total # of partner ed referred to another HSDA	Number of partners contacted By PHN	Number of partners notified by HCP	Number of partners notified by client	Total PHN time spent on case	Total mileage cost per case	comment
		HCP	PHN	HCP	PHN	HCP	PHN								

APPENDIX 5: CRITICAL INCIDENT FORM RE: HIV REPORTING

Complete this form for **harmful incidents** that occur as a **direct result** of contact tracing undertaken by public health follow-up of newly identified HIV cases.

1. Nature of incident:

☐ Breach in confidentiality. Please specify.

☐ Healthcare worker discloses name (or identifying information) of case to contact without permission.
☐ Healthcare worker discloses identify of case to third party without permission.
☐ Contact discloses identity of case to third party without permission.

☐ Harm to case from contact as a result of contact tracing.

☐ Harm to contact from case as a result of contact tracing.

☐ Harm or threats to public health nurse or healthcare worker doing contact tracing from:
☐ Case
☐ Contact

☐ Other. Please specify:

_____

2. Date of incident (yyyy/mm/dd): _____

3. Describe incident:

_____

_____

_____

_____

_____

_____

_____

4. Action taken:

☐ Called police ☐ Referral to Emergency ☐ Referral to family physician

☐ Referral to public health ☐ Referral to community agency ☐ None

☐ Other. Please specify:

Name of Case (optional): _____ Name of Contact (optional): _____

Critical Incident Form Completed by: _____

APPENDIX 6: QUESTIONNAIRE FOR PUBLIC HEALTH NURSES

1. Name of Health Unit: _____

2. Did you receive training regarding partner notification ?

   ☐ Yes If yes, where _____
   ☐ No
   ☐ Don't know

   If yes, do you feel you have been adequately prepared to handle this responsibility?

   _____

   _____

3. Did you receive training for HIV Reporting other than partner notification ?

   ☐ Yes If yes, where _____
   ☐ No
   ☐ Don't know

   If yes, do you feel you have been adequately prepared to handle these new HIV responsibilities?

   _____

   _____

4. Were you newly hired to specifically work on HIV partner notification?

   ☐ Yes
   ☐ No
   ☐ Don't know

   If you were not newly hired, what responsibilities/duties have you given up in order to assume the responsibilities of HIV partner notification?

   Please specify.

   _____

   _____

   _____

   _____

Public Health Nurse Questionnaire (Con'td)

5. Has another public health nurse assumed these responsibilities/duties that you have given up?

- ☐ Yes
- ☐ No
- ☐ Don't know

6. In the table below, estimate the time (in hours) that you spend on the following HIV Reporting tasks per case.

Task	**Time Spent (hours)**
Correspondence with health care provider to discuss partner notification.	
Visits or phone calls with Index Cases.	
Visits or phone calls with Contacts	
Completion of forms (e.g. Case Report forms, Critical Incident forms, etc.).	
Other. Please specify.	
Other. Please specify.	

7. By placing a mark on the scale below, how would you rate the overall reactions of the Index Cases to your visits or phone calls?

Very Positive Positive Neutral Negative Very Negative

Comments.

_____

_____

_____

8. By placing a mark on the scale below, how would you rate the overall reactions of the Contacts to your visits or phone calls?

Very Positive Positive Neutral Negative Very Negative

Comments.

_____

_____

_____

9. Do you think that your visits and/or phone calls to Index Cases have improved the management of their health?

☐ Yes
☐ No
☐ Don't know

If YES, please describe how your visits and/or phone calls have improved the management of their health.

_____

_____

_____

10. Please comment on your impression about the availability of support agencies for the newly HIV positive people you have interviewed since HIV became reportable.

_____

_____

11. Have you been harmed in any way because of HIV Reporting? If so, please specify

_____

_____

APPENDIX 7: QUESTIONNAIRE FOR HEALTH CARE PROVIDERS

1. During HIV pre-test counseling, do you routinely inform the patient of the following:

   a. HIV is now a reportable disease.
   - ☐ Yes
   - ☐ No
   - ☐ Don't know

   b. They are legally entitled to have an HIV test done with or without providing their name
   - ☐ Yes
   - ☐ No
   - ☐ Don't know

   c. Partner notification will be recommended
   - ☐ Yes
   - ☐ No
   - ☐ Don't know

2. What has been your general practice pertaining to partner notification responsibilities for HIV Reporting?
   - ☐ I generally abdicated partner notification responsibilities to the public health nurse in my health region
   - ☐ I generally preferred to do partner notification myself
   - ☐ Other _____

   _____

3. By placing a mark on the scale below, how would you rate the involvement of the public health nurse in the management of partner notification for your patients?

Very Positive Positive Neutral Negative Very Negative

4. Have you or any of your patients been harmed in any way because of HIV Reporting? If so, please specify.

_____

_____

5. On average, what percentage of the partners your Index Cases list are you actually able to make contact with?

_____

_____

Comments:

_____

_____

_____

APPENDIX 8: QUESTIONNAIRE FOR COMMUNITY AGENCIES

Name of Agency: _____

1. What is your position in the agency? _____

1. How was your organization informed of HIV becoming reportable in British Columbia? Please check all that apply.

- ☐ Media (television, radio or newspaper
- ☐ Word of mouth through another community organization
- ☐ Communications from local Health Authority
- ☐ Communication from the BC Centre for Disease Control
- ☐ Communications from the Office of the Provincial Health Officer

- ☐ Other. Please specify.

  _____

2. Were you aware of the following:

(a) HIV is now a reportable disease.
- ☐ Yes
- ☐ No
- ☐ Don't know

(b) One can have the HIV test done with or without providing your name.
- ☐ Yes
- ☐ No
- ☐ Don't know

(c) If the test is positive for HIV then one's health care provider and/or a public health nurse will work with one to develop a plan to contact one' partners or sexual Contacts to inform them that they may have been exposed to HIV.
- ☐ Yes
- ☐ No
- ☐ Don't know

3. Was your organization sufficiently informed that HIV was to become reportable in British Columbia on May 1, 2003?

- ☐ Yes
- ☐ No
- ☐ Don't know

4. Have the clients who access the programs and support services at your organization been asking questions about HIV Reporting?

- ☐ Yes
- ☐ No
- ☐ Don't know

If YES, please list the questions most frequently asked by your clients.

_____

_____

_____

5. Do you feel the staff at your agency have been equipped with the information they require to answer your client's questions related to HIV Reporting?

- ☐ Yes
- ☐ No
- ☐ Don't know

6. Are you aware of any HIV positive individuals who have suffered harm (i.e. physical or verbal violence, discrimination) as a result of HIV becoming reportable?

- ☐ Yes
- ☐ No
- ☐ Don't know

If YES, please describe the harm.

_____

_____

_____

_____

7. Are you aware of any HIV positive individuals who have suffered breech of patient confidentiality as a result of HIV becoming reportable?

- ☐ Yes
- ☐ No
- ☐ Don't know

If YES, please specify _____

_____

APPENDIX 9: AIDS COMMUNITY SERVICE ORGANIZATIONS SURVEYED

Aboriginal ASOs

- Simpcw Health Centre - North Thompson Indian Band
- Ktunaxa/Kinbasket Tribal Council
- Dawson Creek Aboriginal Womens Awareness Society
- Fort Nelson Aboriginal Friendship Society
- Gitxsan Health Servies N.E.
- Open Hearts Open Minds
- Interior Indian Friendship Society
- Okanagan Aboriginal AIDS Society
- Tillicum Haus Native Friendship Centre
- Nuu-Chah-Nulth Community & Human Services Program
- Tla'amin Health Services Society
- Positive Living North
- Prince George Native Friendship Society
- Youth Outreach
- Quesnel Tillicum Native Friendship Centre
- Dze L K'ant Friendship Centre Society
- Chee Mamuk
- Vancouver Native Health Society
- Red Road HIV/AIDS Network
- Akisqnuk Health Centre
- Healing Our Spirit
- Carrier Sekani Family Services

Non-Aboriginal ASOs

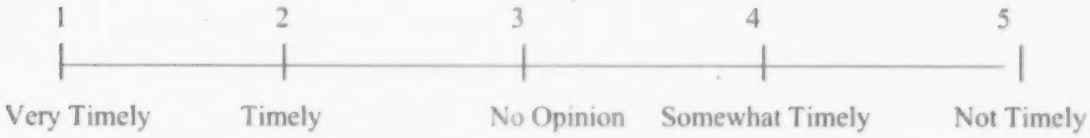
- AIDS Society of Kamloops
- AIDS Resource Center Okanagan Region
- ChillAIDS Services Society
- North Island AIDS
- ANKORS (Nelson)
- Lower Mainland Purpose Society for Youth and Families "Purpose Society"
- AIDS Society of Prince George
- Positive Living North West
- YOUTHCO
- Dr. Peter AIDS Foundation
- BC Persons with AIDS Society
- Positive Women's Network
- A Loving Spoonful
- HIV/AIDS Training Consulting - PhotoTherapy Centre
- Gayway
- Vernon - North Okanagan
- AIDS Vancouver Island
- Victoria Person With AIDS Society
- Victoria AIDS Resource Community Services
- Cariboo AIDS and Information and Support Society
- BC Coalition of People with Diabilities - ADAP
- Boys and Girls Club of Williams Lake & District
- CSHARP
- Living Positive Reource Centre
- Western Canadian Pediatric AIDS Society
- Wings Housing Society

APPENDIX 10: QUESTIONNAIRE FOR MEDICAL HEALTH OFFICERS

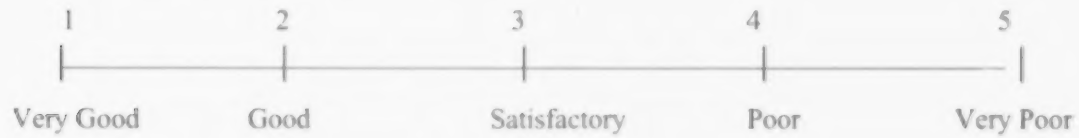
One of the goals of making HIV reportable in British Columbia is to improve the timeliness and quality of HIV data at the local Health Authority level which, in turn, will enhance the planning, development and implementation of local HIV/AIDS programs and support services.

Please rate each of the following statements by placing a mark on the scale.

1. Since HIV became reportable, how would your rate the timeliness in which you receive HIV data specific to your local Health Authority?



2. Since HIV became reportable, how would you rate the quality of HIV data specific to your local Health Authority?



3. Do you analyze or review your local data on a regular basis?

- ❑ No
- ❑ Yes. If yes, how often_____

4. Since HIV became reportable have you, or others within your region, been using the data specific to your local Health Authority to plan, develop and implement local HIV/AIDS programs and support services?

- ☐ Yes
- ☐ No
- ☐ Don't know

If YES, please describe examples of how you have used the data.

_____

_____

5. Do you have sufficient resources in your region to undertake appropriate case and contact follow-up?

☐ Yes

☐ No.

If no, what additional resources are needed? _____

_____

_____

6. Since HIV became reportable, have you had to deal with difficult to manage cases?

☐ No
☐ Yes

If yes, please describe the nature of these cases _____

_____

_____

_____

7. Have you issued MHO Orders under the Health Act to any cases?

☐ No
☐ Yes

If yes, please describe the nature of those orders and the outcomes

_____

_____

_____

8. Have you been harmed in any way because of HIV Reporting? If so, please specify

_____

_____

9. Since HIV became reportable, what activities have you undertaken to educate Physicians, other health care workers and/or community agencies regarding reporting?

_____

_____

_____

_____

10. What have been the major benefits of making HIV reportable?

_____

_____

_____

_____

11. Please describe any concerns you have, or concerns expressed to you from others, regarding HIV Reporting.

_____

_____

_____

_____

12. Do you have any suggestions to improve the process of reporting?

_____

_____

_____

_____

APPENDIX 11: CRITICAL INCIDENT FORM RE: HIV REPORTING

Complete this form for **harmful incidents** that occur as a **direct result** of contact tracing undertaken by public health follow-up of newly identified HIV cases.

1. Nature of incident:

☐ Breach in confidentiality. Please specify.
- ☐ Healthcare worker discloses name (or identifying information) of case to contact without permission.
- ☐ Healthcare worker discloses identify of case to third party without permission.
- ☐ Contact discloses identity of case to third party without permission.

☐ Harm to case from contact as a result of contact tracing.

☐ Harm to contact from case as a result of contact tracing.

☐ Harm or threats to public health nurse or healthcare worker doing contact tracing from:
- ☐ Case
- ☐ Contact

☐ Other. Please specify:

_____

5. Date of incident (yyyy/mm/dd): _____

6. Describe incident:

_____

_____

_____

_____

_____

_____

_____

7. Action taken:

☐ Called police ☐ Referral to Emergency ☐ Referral to family physician

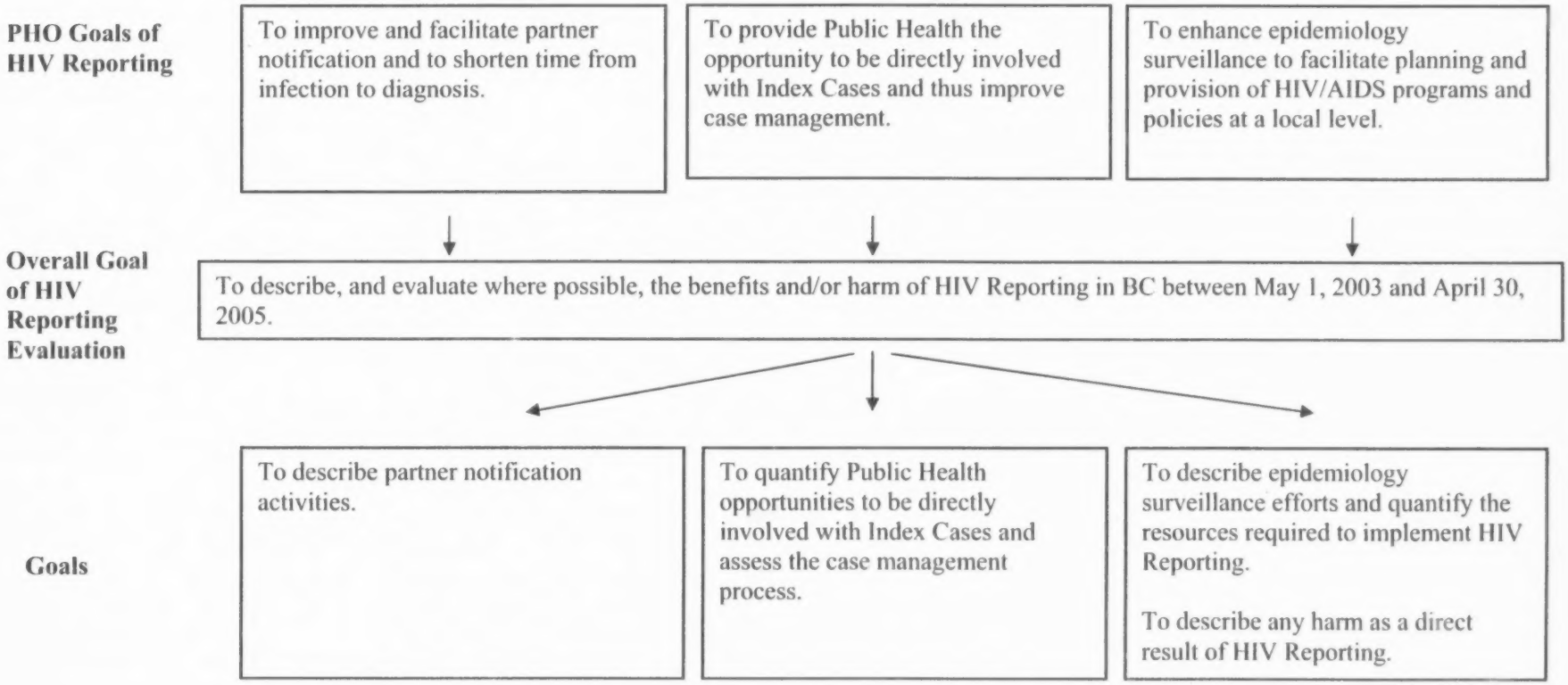
☐ Referral to public health ☐ Referral to community agency ☐ None

☐ Other. Please specify:

Name of Case (optional): _____ Name of Contact (optional): _____

Critical Incident Form Completed by: _____

APPENDIX 12: HIV REPORTABLITY EVALUATION LOGIC MODEL


PHO Goals of HIV Reporting
To improve and facilitate partner notification and to shorten time from infection to diagnosis.
To provide Public Health the opportunity to be directly involved with Index Cases and thus improve case management.
To enhance epidemiology surveillance to facilitate planning and provision of HIV/AIDS programs and policies at a local level.
Overall Goal of HIV Reporting Evaluation
To describe, and evaluate where possible, the benefits and/or harm of HIV Reporting in BC between May 1, 2003 and April 30, 2005.
Goals
To describe partner notification activities.
To quantify Public Health opportunities to be directly involved with Index Cases and assess the case management process.
To describe epidemiology surveillance efforts and quantify the resources required to implement HIV Reporting.
To describe any harm as a direct result of HIV Reporting.

Evaluation of the Impact of Making HIV a Reportable Infection in BC

Target Groups

- Index Cases
- Contact Cases
- Public Health Nurses
- Physicians
- Community Agencies
- Medical Health Officers(s)

Components

Self-Administered Questionnaire at first contact and, when possible, at a second interval.

Data collected from HIV surveillance data bases, Public Health Summary Sheets and HIV Reporting case report forms.

Questionnaire done at intervals

Data collected by Public Health Nurses on elicitation forms.

Goal(s)

INDEX CASES

To qualitatively evaluate improvement, if any, in case management by Public Health.

To describe epidemiology surveillance efforts and processes.

To report any harm as a direct result of HIV Reporting.

Outcome Objectives

- To determine number of Index Cases that had contact with Public Health.
- To qualitatively collect information about the usefulness of Public Health case management from the index case perspective.

To compare the overall # of tests and # of persons testing newly positive after HIV Reporting to the trends prior to reporting.

To obtain number of incidences of harm as a result of reporting; describe nature of harm.

To obtain number of cases of breech of confidentiality and describe the nature of the breech.

To obtain information about the reporting process with Index Cases.

Evaluation of the Impact of Making HIV a Reportable Infection in BC

Process	Gather information through questions on the questionnaire about who had public health involvement and whether this involvement was considered supportive.	Gather information about the # of persons testing newly positive from provincial lab and compare the same from prior years in STD database.	Gather information regarding harm from *CRF and critical incidence forms.	Gather information about breach of confidentiality from critical incident forms.	Determine: - # of Index Cases aware that HIV was reportable at the time of testing - # aware of nominal and non-nominal option at the time of testing - determine reasons for testing - quantify number of ContactsContacts given per case - to determine # cases where contact tracing was done by the index case
Who will conduct processes and how	The PHN or MD will provide questionnaire to index case. This will be mailed in to the research assistant who will pass it on to the data manager.	The research assistant will coordinate collection of data from HIV surveillance database.	The CRF and critical incidence forms will be completed by the PHN or MD and sent to HIV surveillance staff. Data for evaluation will be gleaned from these forms by the research assistant.		This data will be collected from the evaluation questionnaire. The questionnaire will be sent to the research assistant.

CONTACT CASES

Goal(s)

To describe partner notification activities.

* CRF = Case Report Form

To describe epidemiology surveillance efforts related to Contacts.

To describe any harm as a direct result of HIV Reporting.

Outcome Objectives

To disclose the hidden epidemic to make people aware of their HIV positive sero-status.

To obtain information about reporting process.

To obtain number of incidences of harm and describe the nature of the harm.

To obtain number of cases of breech of confidentiality.

Process

Determine:
- # Contacts Contacts listed by index case
- # Contacts Contacts actually contacted
- # Contacts Contacts tested as a result of being contacted
- # of positive tests from above
- # of the positive Contacts Contacts, how many already knew they were positive
- use calculation for calculating hidden epidemic

Determine
- # of Contacts Contacts aware that HIV was reportable
- # aware of nominal and non-nominal option
- determine reasons for testing

Gather information from critical incidence forms regarding harm.

Gather information from critical incident forms regarding breech of confidentiality.

Who will conduct processes and how

This data will be collected from the CRF and the evaluation questionnaire. The CRF will be sent to the HIV surveillance staff by the PHN or MD. Data will be gleaned from the CRF and provided to the data manager.

The evaluation will be mailed in to the research assistant and forwarded to the data manager.

This data will be collected from the critical incident form. This will be send to HIV surveillance and the research assistant will glean data from there.

PUBLIC HEALTH NURSES

Goal(s)	To quantify Public Health opportunities to be directly involved with cases and qualitatively evaluate the case management process by Public Health.		To describe epidemiology surveillance efforts and quantify the resources required to implement HIV Reporting. To describe any harm as a direct result of HIV Reporting.		To describe partner notification activities.
Outcome Objectives	To determine degree of involvement of Public Health.	To determine Public Health's perception of involvement and improvement in case management.	To determine resource expenditure from Public Health.	To assess incidences of harm as a result of reporting; describe nature of harm.	To determine # of ContactsContacts successfully reached by PHN.
Process	Determine: - # cases testing positive - # Index Cases contacted - # who involved Public Health rather than a doctor - # cases where case was managed solely by MD - # cases where both MD and Public Health managed case	Qualitative question posed to Public Health NursesPublic Health Nurses.	Determine: 1) # cases managed 2) time per case 3) additional staffing used or re-allocation of staff 4) deferment of tasks and duties	- gather information from PHN about # incidences of harm experienced by cases and ContactsContacts - report any incidences of harm experienced by PHN as a result of reporting	Determine: - # ContactsContacts reached by PHN
Who will conduct processes and how	This data will be collected from the CRF and the evaluation questionnaire. PHN will send the CRF to HIV surveillance per instructions and the questionnaire sent to the research assistant every 6 months. Data will be gleaned from the CRF by the research assistant.	This data will be collected from the evaluation questionnaire. PHN will send the questionnaire to the research assistant.		This data will be collected from the critical incident form and the evaluation questionnaire. PHN will send the critical incident form to HIV surveillance per instructions and the evaluation to the research assistant every 6 months.	This data will be collected on the PHN HIV Reporting work summary sheets.

PHYSICIANS

Goal(s)	To quantify Public Health vs MD involvement with cases and qualitatively evaluate improvement, if any, in case management.	To describe any harm as a direct result of HIV Reporting.	To describe partner notification activities.	
Outcome Objectives	To determine degree of involvement of MD.	To determine MD's perception of the need for Public Health's involvement in case.	To assess incidences of harm as a result of reporting; describe nature of harm.	To determine # of ContactsContacts successfully reached by MD.
Process	Determine: - # persons testing positive - # Index Cases contacted - # cases where doctor managed - # cases where both MD and Public health managed case	Qualitative question posed to Physicians.	- gather information from MD about # incidences of harm experienced by cases and Contacts - report any incidences of harm experienced by MD as a result of reporting	Determine: - # Contacts reached by MD
Who will conduct processes and how	This data will be collected from the CRF and the evaluation questionnaire. MD will send the CRF to HIV surveillance per instructions and the questionnaire to the research assistant every 6 months. Data will be gleaned from the CRF by the research assistant.	This data will be collected from the evaluation questionnaire. MD will send in a questionnaire every 6 months.	This data will be collected from the critical incident form and the evaluation questionnaire. The MD will send the critical incident form to HIV surveillance per instructions and the evaluation to the research assistant every 6 months.	This data will be collected from the evaluation questionnaire. The MD will send an evaluation to the research assistant every 6 months.

COMMUNITY AGENCIES

Goal(s)

To describe partner notification activities.

To describe epidemiology surveillance efforts and quantify the resources required to implement HIV Reporting.

To describe any harm as a direct result of HIV Reporting.

Outcome Objectives

To assess the level of knowledge about HIV Reporting that is required for public education and awareness.

To assess the overall perceptions (positive or negative) of community agencies regarding HIV Reporting.

To assess community agency resource expenditure on HIV Reporting.

To determine if community agencies are aware of harm as a result of reporting.

Process

Determine the agency personnel's sources of information when providing information about reporting.
Determine what clients are asking community agencies about reporting and perception from agencies about whether staff have been equipped to respond to questions.

Assess agency's impressions of benefits and/or drawbacks to making HIV reportable.

Assess the perceptions that the community agencies have regarding their relationship with public health as a result of reporting and their perceptions about the appropriateness of public health's involvement with case management.

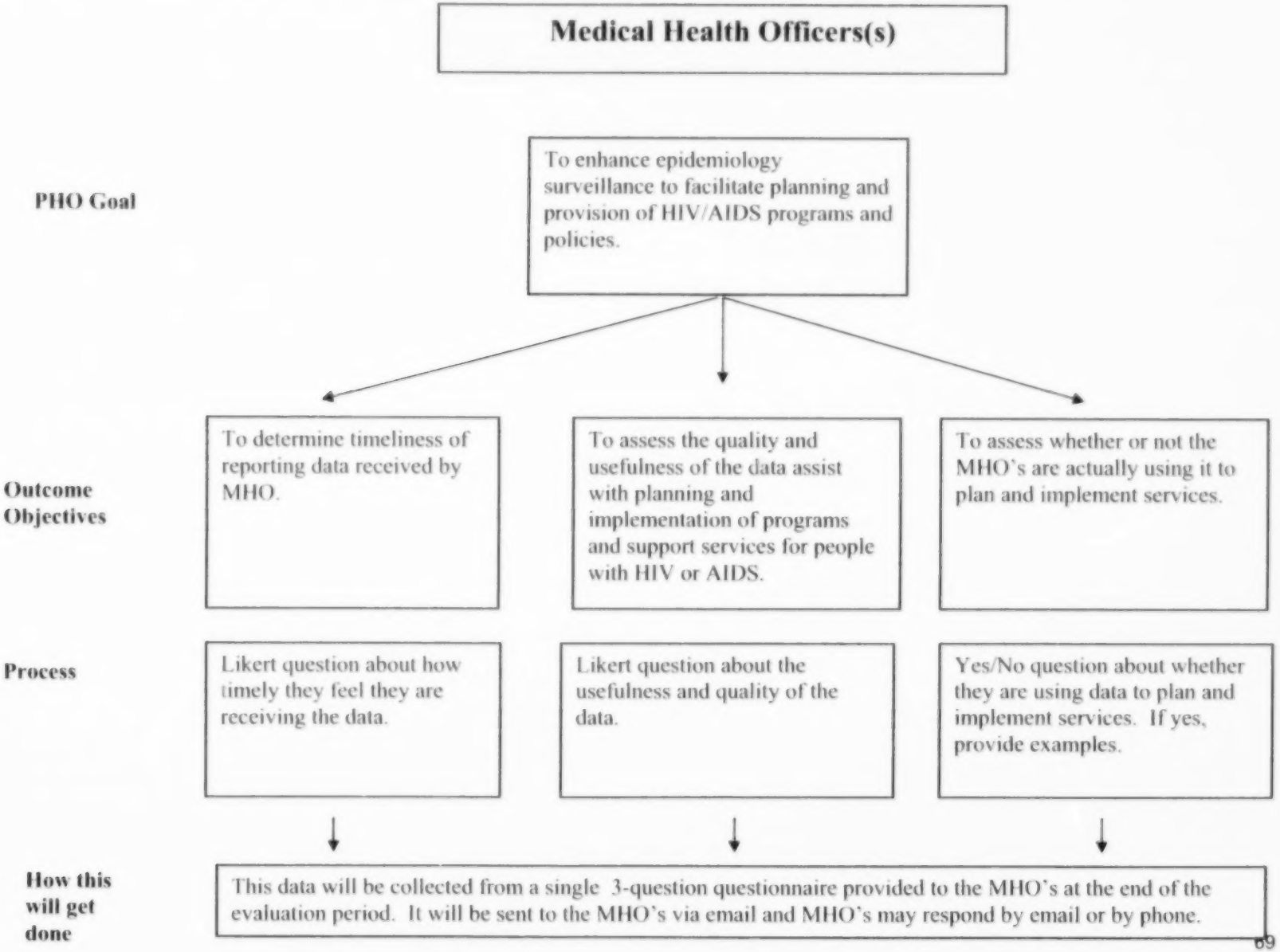
Quantify the amount of time community agency personnel are spending on reporting.

Determine if agencies are allocating resources to reporting.

Determine if agencies are hearing about incidences of harm and/or breeches of confidentiality. If so, general report of the nature of harm.

Who will conduct processes and how

All Aids Service organizations will be provided with a questionnaire periodically. This evaluation will be completed and mailed into the BCCDC research assistant for analysis.


Medical Health Officers(s)
PHO Goal
To enhance epidemiology surveillance to facilitate planning and provision of HIV/AIDS programs and policies.
Outcome Objectives
To determine timeliness of reporting data received by MHO.
To assess the quality and usefulness of the data assist with planning and implementation of programs and support services for people with HIV or AIDS.
To assess whether or not the MHO's are actually using it to plan and implement services.
Process
Likert question about how timely they feel they are receiving the data.
Likert question about the usefulness and quality of the data.
Yes/No question about whether they are using data to plan and implement services. If yes, provide examples.
How this will get done
This data will be collected from a single 3-question questionnaire provided to the MHO's at the end of the evaluation period. It will be sent to the MHO's via email and MHO's may respond by email or by phone.

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